DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Critical Review of Literature: Solution focused approaches in an intellectual disabilities context: a narrative review; 2) Evaluating & Improving OCD-UK's conference: collaboration between people with personal experience and professionals: 3) Cognitive-behavioural factors involved in CFS/ME and IBS

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Abstracts

Main Research Project

Objectives: Chronic Fatigue Syndrome/ME (CFS/ME) and Irritable Bowel Syndrome (IBS) are known to be associated with poor quality of life and impaired functioning. Similar psychological drivers have been identified in these conditions, such as beliefs about symptoms (cause, consequence and management) and behavioural responses (withdrawal, avoidance and safety-seeking). The aim of this study was to compare CFS/ME and IBS groups regarding these factors to establish the extent to which they are similar (transdiagnostic) and different (disorder-specific). **Method:** Using a cross-sectional design, CFS/ME participants (n= 21), IBS participants (n=40), participants with co-morbid CFS/ME and IBS (n= 17) and healthy controls (n=65) were compared on a range of self-report questionnaires. This included measures of general psychological well-being (depression, anxiety, mental defeat, functioning). Novel measures were also developed to measure transdiagnostic and disorder-specific beliefs and behaviours, all of which were found to have good internal consistency. **Results:** Compared to the controls, the clinical groups reported poorer psychological wellbeing and endorsed more negative transdiagnostic beliefs and behaviours than healthy controls. The CFS/ME and co-morbid groups also scored significantly higher than the IBS group. Additionally, the CFS/ME group endorsed more disorder-specific beliefs and behaviours related to fatigue, while the IBS group scored higher on disorder-specific characteristics relevant to gastrointestinal symptoms. The co-morbid group showed characteristics of both CFS/ME and IBS. **Conclusions:** These study found similarities and differences between CFS/ME and IBS participants, regarding their beliefs about symptoms and behavioural responses to symptoms. This indicates that it may be appropriate to use a modular transdiagnostic cognitive-behavioural approach for these problems, whereby therapy would start by addressing their common features and become more tailored to disorder-specific features as therapy progresses. For patients with CFS/ME, potentially unhelpful fatigue-related beliefs and behaviours should be addressed. Similarly, IBS patients may benefit from a focus on relevant gastrointestinal beliefs and behaviours. Implications for future research are discussed. Key words: *Chronic Fatigue Syndrome, ME, Irritable Bowel Syndrome, Cognitive-Behavioural Therapy, transdiagnostic, disorder-specific*

Service Improvement Project

People with mental health problems in general and Obsessive Compulsive Disorder (OCD) in particular often delay seeking help and lack information about evidence-based treatment. Provision of such information has increasingly become a task led by third sector organisations. OCD-UK is a charity, led by people with personal experience of OCD that runs an annual conference to address these issues. It primarily aims to promote understanding of OCD and its treatment, and increase optimism regarding the ability to overcome OCD. It also aims to highlight the need for psychological treatment, specifically Cognitive Behavioural Therapy. The present study undertook a systematic evaluation of OCD-UK's 2014 conference. Sufferers (n=50) and carers (n=41) completed questionnaires pre- and post-conference. Changes in their scores showed that the conference was successful in increasing attendees' confidence in their understanding of OCD and knowledge of treatment options. Additionally, the following beliefs weakened: pessimism about the ability to overcome OCD and perception of OCD as a biological illness. Beliefs about perceived need for psychological therapy to overcome OCD strengthened. Generally, sufferers and carers did not differ in terms of the impact of the conference. The findings illustrate the value of third-sector organisations, like OCD-UK, in providing information and addressing beliefs that are considered barriers to accessing treatment. The implications of these findings are discussed, along with recommendations for future research. *Key words: Obsessive-Compulsive Disorder (OCD), Cognitive Behavioural Therapy (CBT), service-user, personal experience and evaluation.*

Critical Review of the Literature

Purpose: Solution-Focused Brief Therapy (SFBT) has a growing evidence base for the general population. Several authors have recognised the advantages of applying this short-term, goal-focused and client-directed approach in intellectual disabilities (ID) and its evidence-base in this context is growing. However, it has not been critically evaluated. The purpose of this review is to summarise and critique the literature that has used solution-focused (SF) approaches in ID, and consider the implications for future research and clinical practice. **Methodology and findings:** A narrative literature review

identified 12 studies that described or evaluated the application of solution-focused approaches; six used SFBT with individuals with IDs and six used Solution Focused Counselling (SFC) with staff and families. **Research implications:** The evidence-base primarily consists of case studies, and while they were generally of good quality, this limits the conclusions that can be drawn regarding the effectiveness of SF approaches in this context. There is a need for further controlled studies, with valid and reliable outcome measures, larger samples and longer follow-ups. **Practical implications:** Overall the reviewed studies offered preliminary evidence for the effectiveness of SFBT for individuals with mild ID and SFC for care staff working with individuals with moderate and severe ID, in particular in cases where clients' behaviour challenges. ID services should consider offering SF approaches on this basis. For individuals with ID, SF techniques should be modified to accommodate for their cognitive abilities and carers should be involved in sessions where possible. The 'miracle question' technique was consistently considered too abstract and unhelpful, regardless of whether it was used for individuals with ID or their family and carers. Hence, it should be re-phrased so that it is more concrete and focused on coping, strengths & competencies. Keywords: *Intellectual disability, learning disability, solution-focused, solution-focused brief therapy, solution-focused coaching, solution-focused consultation*

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Research

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Personal

I would not have gotten to this point without the unwavering support of my family and friends. Mum and Dad thank you for always being there; telling me I could do it. Paul and Louise, thank you for all the much needed texts and photos of Ben. I promise I'll come home more often to spend time with ye all. Rachel, thank you so much for all your patience with proofreading requests and all the pep talks over the last three year. Girls, whether you are close or far away, you always make me laugh and thank you for that. Fellow trainees, I could not have gotten through the last three years without you. Kate and Lisa, I'm a little sad that our coffee shop study sessions have come to an end. We will have to come up with some other excuses (hopefully more fun ones) for spending all our time in coffee shops.

Eoin, thank you simply isn't enough. You stuck with me through all the moves, the emotional ups and downs and work-filled weekends. I'll never forget it, but I promise it's over now, and Coll will return.

Dedication

For my granddad, Noel, for everything you have taught me

Main Research Project

Cognitive-Behavioural Factors Involved in CFS/ME and IBS

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Cognitive-Behavioural Factors Involved in CFS/ME and IBS

Abstract

Objectives: Chronic Fatigue Syndrome/ME (CFS/ME) and Irritable Bowel Syndrome (IBS) are known to be associated with poor quality of life and impaired functioning. Similar psychological drivers have been identified in these conditions, such as beliefs about symptoms (cause, consequence and management) and behavioural responses (withdrawal, avoidance and safety-seeking). The aim of this study was to compare CFS/ME and IBS groups regarding these factors to establish the extent to which they are similar (transdiagnostic) and different (disorder-specific). **Method:** Using a cross-sectional design, CFS/ME participants (n= 21), IBS participants (n=40), participants with co-morbid CFS/ME and IBS (n= 17) and healthy controls (n=65) were compared on a range of self-report questionnaires. This included measures of general psychological well-being (depression, anxiety, mental defeat, functioning). Novel measures were also developed to measure transdiagnostic and disorder-specific beliefs and behaviours, all of which were found to have good internal consistency. **Results:** Compared to the controls, the clinical groups reported poorer psychological wellbeing and endorsed more negative transdiagnostic beliefs and behaviours than healthy controls. The CFS/ME and co-morbid groups also scored significantly higher than the IBS group. Additionally, the CFS/ME group endorsed more disorder-specific beliefs and behaviours related to fatigue, while the IBS group scored higher on disorder-specific characteristics relevant to gastrointestinal symptoms. The co-morbid group showed characteristics of both CFS/ME and IBS. **Conclusions:** These study found similarities and differences between CFS/ME and IBS participants, regarding their beliefs about symptoms and behavioural responses to symptoms. This indicates that it may be appropriate to use a modular transdiagnostic cognitive-behavioural approach for these problems, whereby therapy would start by addressing their common features and become more tailored to disorder-specific features as therapy progresses. For patients with CFS/ME, potentially unhelpful fatigue-related beliefs and behaviours should be addressed. Similarly, IBS patients may benefit from a focus on relevant gastrointestinal beliefs and behaviours. Implications for future research are discussed. Key words: *Chronic Fatigue Syndrome, ME, Irritable Bowel Syndrome, Cognitive-Behavioural Therapy, transdiagnostic, disorder-specific*

Cognitive-Behavioural Factors Involved in CFS/ME and IBS

Introduction

Chronic Fatigue Syndrome / Myalgic Encephalopathy (CFS/ME) and Irritable Bowel Syndrome (IBS) often co-occur (Hamilton, Gallagher, Thomas, & White, 2009) and are associated with high levels of disability, impaired quality of life and significant costs to the healthcare system (El-Serag, Olden, & Bjorkman, 2002; Falk Hvidberg, Brinth, Olesen, Petersen, & Ehlers, 2015; Maxion-Bergemann, Thielecke, Abel, & Bergemann, 2006; McCrone, Darbisgire, Ridsdale, & Seed, 2003). CFS/ME is estimated to impact between two and four people per 1000 in the UK (National Institute for Health & Clinical Excellence [NICE], 2007). CFS/ME results in a marked loss of energy and a prolonged recovery period following mental or physical exertion (Carruthers et al., 2011). People with CFS/ME also report malaise, headaches, sleep disturbance, impaired concentration and muscle pain (NICE, 2007). IBS is characterised by abdominal pain, bloating, constipation and diarrhoea (Francis, Morris, & Whorwell, 1997) and has a prevalence rate of 10-20% in the UK (NICE, 2008).

A number of genetic and physiological factors have been implicated in the onset and persistence of CFS/ME (e.g. Morris & Maes, 2014; Nijs et al., 2012; Stubhaug, Tveito, Eriksen, & Ursin, 2005) and IBS (e.g. Hauser, Pletikosic, & Tkalcic, 2014; Kennedy et al., 2012). However, no definitive physical causes have been identified for either condition (Witthöft & Hiller, 2010), meaning CFS/ME and IBS are currently considered “medically unexplained symptoms” (MUS) (Witthöft & Hiller, 2010). However, MUS as a concept and diagnosis is controversial. It can be seen as implying a causal role for psychological factors, which can understandably feel stigmatising (Looper & Kirmayer, 2004; van Ravenzwaaij et al., 2010). The term Persistent Physical Symptoms (PPS) is preferred by those who suffer from such conditions (Picariello, Ali, Moss-Morris & Chalder, 2015).

Understanding the involvement of psychological factors in the exacerbation of long-term health problems, of known or unknown physical origin, is crucial for empowering individuals experiencing such problems. Recent research has

illustrated how physical and psychological factors interact, to impact the quality of life and the experience of disability, in Multiple Sclerosis (Hayter, Salkovskis, Silber, & Morris, 2016), Parkinson's Disease (Simpson, Lekwuwa, & Crawford, 2013) and Type 2 Diabetes (Paschalides et al., 2004).The present study does not imply psychological causal factors, but instead considers the interaction between physical and psychological factors in CFS/ME and IBS.

Cognitive Behavioural Therapy

PPS is arguably best understood using biopsychosocial models specifically the Cognitive Behavioural Therapy (CBT) model (Brown, 2004; Deary, Chalder, & Sharpe, 2007; Rief & Broadbent, 2007) . General CBT models for PPS (Deary et al., 2007) as well as models specifically for CFS/ME (Surawy, Hackmann, Hawton, & Sharpe, 1995) and IBS (Hauser et al., 2014; Kennedy et al., 2012; Lackner, 2005) have been developed. For both conditions, CBT is the recommended treatment approach (NICE, 2007, 2008).

The CBT model proposes that symptoms are initially triggered by organic illness or stress and are perpetuated by interplay between physiological, cognitive, emotional, behavioural, and social factors (Deary et al., 2007). There is strong evidence to suggest that these individual factors are involved in the maintenance of PPS and some limited empirical support for the bio-psychosocial interaction between these factors (Deary et al., 2007; Witthöft & Hiller, 2010). For example, the physiological response to stress, which is carried out by the autonomic nervous system, generates a range of bodily symptoms (e.g. increased heart rate, elevated breathing, disinhibition of digestion, muscle tension and shaking) (Deary et al., 2007). Life events can lead to prolonged activation of this response, which exacerbates symptoms and has neurological, endcrinological, immunological and cardiovascular consequences (Deary el., 2007). Additionally, prior experience of physical symptoms causes physiological sensitisation to those symptoms, meaning that they can be triggered at a lower threshold (Brown, 2004; Rief & Barsky, 2005; Rygh et al., 2005).

This threshold is further lowered by cognitive (e.g. vigilance to symptoms and illness beliefs about the cause, consequences and management of symptoms) and affective (e.g. anxiety and depression) factors (Brown, 2004;

Rief & Barsky, 2005; Rygh et al., 2005). PPS cause significant psychological distress and in attempts to prevent or manage symptoms people can engage in a range of behaviours (e.g. withdrawal, avoidance and safety-seeking) (Deary et al., 2007). Often people seek re-assurance from General Practitioners (GPs) and social support but inadequate responses can amplify the distress associated with symptoms (Kirmayer, Groleau, Looper & Dao, 2004). These examples suggests that there are multiple 'vicious cycles' involved in the maintenance of PPS (Deary et al., 2007).

The model described above draws from the CBT model of emotional disorders. According to the content-specificity hypothesis emotional disorders share similar 'vicious cycles', but each have a distinct cognitive profile (Beck, 1976) which mediates disorder-specific emotional and behavioural responses (Beck, Brown, Steer, Eidelson, & Riskind, 1987). In other words, the CBT model accounts for transdiagnostic and disorder-specific features in emotional disorders. Thus far research has not considered the relevance of the content-specificity hypothesis to PPS.

It is beyond the scope of this study to consider all relevant factors associated with the maintenance of CFS/ME and IBS. Previous research has investigated the role of physiological factors, and the higher levels of anxiety and depression found in CFS/ME and IBS is well evidenced (see Deary et al., 2007). The focus of this study will be on the role of beliefs about symptoms and resulting behavioural responses.

In CFS/ME, key beliefs include the cause of symptoms (e.g. organic attributions), their consequences (e.g. loss of performance, failure to meet standards, underestimate performance) and the management of symptoms (e.g. harmfulness of activity, fears of exacerbating symptoms, low self-efficacy) (Knoop, Prins, Moss-Morris, & Bleijenberg, 2010; Surawy et al., 1995). Beliefs about the harmfulness of activity are considered particularly important. Interestingly, Deale, Chalder, & Wessely (1998) found that changes in beliefs about the harmfulness of activity rather than causal attributions were associated with good outcomes in group CBT. Beliefs about the unacceptability of emotions have also been implicated in CFS/ME (Rimes & Chalder, 2010). Aside

from beliefs, the most consistently found CFS/ME relevant cognitive factor is hypervigilance to symptoms (Knoop et al., 2010). Commonly reported behavioural responses to CFS/ME include activity avoidance, oscillation between activity and inactivity (i.e. booming and busting) and withdrawal (Surawy et al., 1995; Vercoulen et al., 1997). Additionally, one study found that a passive coping style (i.e. cognitive and behavioural avoidance) predicted levels of impairment, but this was in turn mediated by illness perceptions (Heijmans, 1998).

Similarly, cognitive factors that have been linked to IBS include hypervigilance to symptoms, catastrophic interpretations of pain, the social and functional consequences of symptoms and beliefs about how to manage symptoms (Hauser et al., 2014; Kennedy et al., 2012; Lackner, 2005). These factors have been found to be of greater concern to IBS patients than healthy controls and patients with other organic gastrointestinal illnesses (e.g. Gibbs-Gallagher et al., 2001; Hunt, Milonova, & Moshier, 2009; Posserud, Svedlund, Wallin, & Simrén, 2009). Organic attributions regarding symptoms had previously been emphasised but a recent study found that people with IBS do not make more of these types of attributions than other gastroenterology patients (Bray, Nicol, Penman, & Ford, 2006). Beliefs about the unacceptability of emotions and their relation to emotional suppression and quality of life in IBS have also been reported but further research is required to understand these relationships further (Ali et al., 2000; Bowers & Wroe, 2016).

In terms of behavioural responses, people with IBS have consistently been shown to attend their GPs more frequently than healthy controls and people with other physical conditions e.g. peptic ulcers (Bass, Hyde, Bond, & Sharpe, 2001; Whitehead, Winget, Fedoravicius, Wooley, & Blackwell, 1982). Also, at times of stress (emotional and physical), people with IBS are more likely to engage in ‘all or nothing’ coping (Spence & Moss-Morris, 2007) and are less likely to seek social support (Pellissier, Dantzer, Canini, Mathieu, & Bonaz, 2010). The latter may be linked to perceived lack of social support (Hauser et al., 2014). Additionally, when symptoms flare up, people engage in avoidance behaviours (e.g. avoid exercise, food, sex, work) and safety-seeking behaviours

(e.g. checking stools, taking medication, wearing baggy clothes) (Reme, Darnley, Kennedy, & Chalder, 2010).

Aims

Research suggests that there are similar cognitive and behavioural factors associated with the maintenance of CFS/ME and IBS. This suggests that there may be transdiagnostic factors involved in these conditions. However, to the author's knowledge no other study has directly compared people with CFS/ME and IBS in order to verify this. Additionally, while it is generally agreed that there is overlap between PPS disorders, the overlap is unlikely to be complete; we propose that there are also disorder-specific factors involved in the maintenance of different conditions (Aaron & Buchwald, 2001). Identifying where these differences lie is likely to have important implications for how CBT interventions are tailored for CFS/ME and IBS. On the basis of there being transdiagnostic and disorder-specific factors involved in PPS conditions, (Salkovskis et al., in press) have proposed a modular CBT approach for PPS, whereby therapy would start by addressing the common features of PPS and become more tailored to the disorder-specific features as therapy progresses, with the whole package being on a formulation basis.

The current study aims to address the gap in the evidence base regarding the extent of transdiagnostic and disorder-specific features of CFS/ME and IBS. This will be achieved by comparing participants with CFS/ME, those with IBS and healthy controls, in terms of psychological characteristics that are considered significant to the cognitive-behavioural models of PPS. A primary aim is to establish whether the beliefs people with CFS/ME and people with IBS endorse are similar or different. A secondary question is to establish whether the groups share or differ in their behavioural responses to symptoms.

Method

Overview

A cross-sectional between-groups design was used, comparing people who self-identified as having (1) CFS/ME, (2) IBS, (3) both of these conditions, and (4) not having either of these conditions (i.e. healthy controls; HCs). A

questionnaire methodology was used. The study protocol was approved by the University of Bath Department of Psychology Ethics Committee (Project reference: 15-234), the WALES NHS REC 7 ethics board (REC Reference 15-WA-0298), and by the relevant NHS Trust Research & Development departments (Appendix B).

Participants

Two participant recruitment procedures were used. First, people with CFS/ME and IBS were recruited through two NHS primary care psychology services and a specialist NHS CFS/ME service in the South West of England. Patients were invited to participate either by their clinician during routine appointments or by the lead researcher during psycho-educational groups. Advertisements were also displayed in the service waiting areas. Potential participants were given an information sheet regarding the study and were invited to opt-in via the study's website. Second, CFS/ME and IBS participants, and HCs were recruited through advertisements on social media, which invited potential participants to opt-in via the study's website.

Inclusion criteria for all groups were: aged 18 or above and sufficient English language ability to complete the questionnaires. Participants who reported mild mental health problems that were being managed in primary care were included, as were participants taking medications for psychological or physical conditions. Participants who had received more than two sessions of formal CBT (within the last year) to address CFS/ME or IBS were excluded. To reflect the clinical populations, participants with physical co-morbidity were included, unless they self-reported having a physical condition that was considered a differential diagnosis of CFS/ME (e.g. underactive thyroid) or IBS (e.g. inflammatory bowel disease) and might account for reported CFS/ME or IBS symptoms. Thirteen were removed for this reason.

Participants who self-identified as having CFS/ME were required to have a minimum score of four on the Chalder Fatigue Scale (CF-Scale; using the bi-modal scoring system) to meet caseness (Cella & Chalder, 2010; Chalder et al., 1993). Participants who self-identified as having IBS were required to score 75 or above on the Irritable Bowel Syndrome Severity Scoring System to meet

caseness (IBS-SSS; Francis, Morris & Whorwell, 1997). Participants were excluded if they did not meet these criteria; as a result two were excluded from the CFS/ME group, one from the IBS group and one from the comorbid group. In addition, participants were removed if they scored more than two Standard Deviations (SD) above the Mean ($\bar{x}$) on the screening measure for a condition they had not identified as having. This is helped to establish that the groups were distinct from each other and is referred to as data trimming (Field, 2012; see Appendix C for details). Final sample groups were: 21 CFS/ME only, 40 IBS only, 17 comorbid, and 65 HC. *Figure 1*. shows a CONSORT flow diagram for all groups.

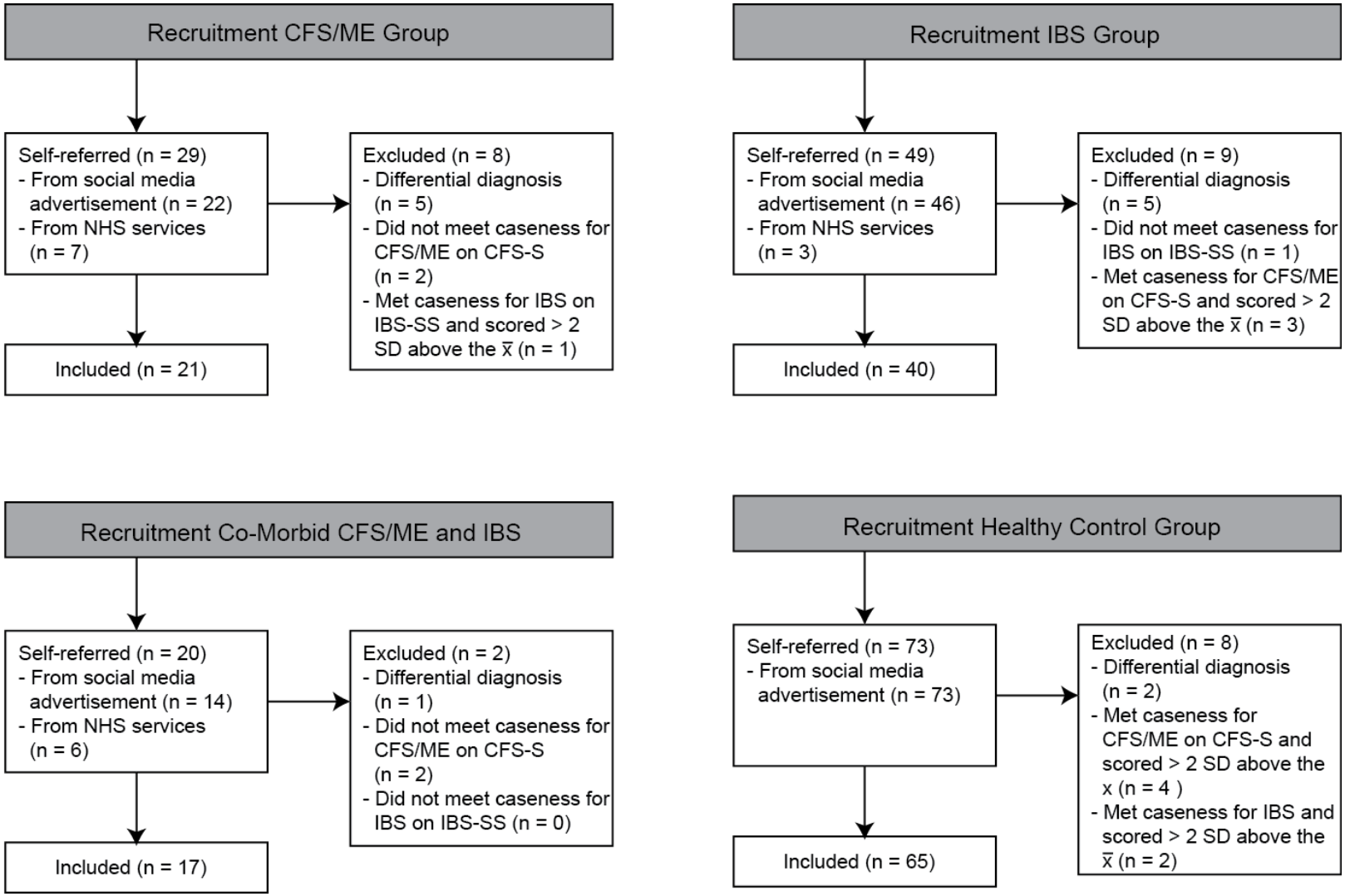

Figure 1. CONSORT diagram of recruitment procedure

Procedure

All participants opted-in via the study website. Participants confirmed that they had read the study information sheet and they met the study's inclusion criteria, and completed the online consent form. Following this, participants completed the online questionnaire battery.

Measures

Self-report questionnaires were used to measure physical symptomology and to assess psychological wellbeing, all of which were previously validated and replicated, with established cut-offs. Cognitive and behavioural factors associated with physical conditions were also assessed using self-report measures that were developed or adapted from other measures for the purpose of this study (see Appendix D). A summary of all the measures is presented below. A more detailed description of the measures can be found in Appendix E.

CFS/ME and IBS symptomology. Fatigue symptoms were assessed using the *CFS-S* (Cella & Chalder, 2010; Chalder et al., 1993), which is well validated against the Oxford (Sharpe et al., 1991) and Fukuda et al. (1994) criteria of CFS. The presence of IBS symptoms was screened using the 5-item *IBS-SSS* (Francis et al., 1997), which is validated against the Rome I criteria of IBS (Thompson, Creed, Drossman, Heaton, & Mazzacca, 1992).

Psychological wellbeing. General levels of depression were assessed using the 9-item *Patient Health Questionnaire* (PHQ-9; Kroenke, Spitzer, & Williams, 2001). Anxiety symptoms were measured using the 7-item *Generalised Anxiety Disorder* questionnaire (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006) Participants' levels of functional impairment were assessed using the 5-item *Work and Social Adjustment Scale* (WSAS; Mundt, Marks, Shear & Greist, 2002). The 14-item *Short Health Anxiety Inventory* (SHAI; Salkovskis, Rimes, Warwick, & Clark, 2002) was used to evaluate anxiety regarding illness and somatic symptoms. The 24-item Pain Self Perception Scale (PSPS; Tang, Salkovskis, & Hanna, 2007), was used to measure mental defeat. For this study it was referred to as the *Mental Defeat* (MD) Scale.

Cognitive factors associated with physical conditions. No previously validated measured could be identified that evaluated cognitions specific to the CBT model of PPS. Therefore, the *Beliefs about Physical Symptoms* (Beliefs-P) scale was developed for the present study. It included 22 items, using are a 10-point Likert scale format. The items were derived from CBT themes in the literature (e.g. Deary et al., 2007) relating to potentially unhelpful beliefs about the (social and functional) consequences and management of PPS symptoms. Some relevant items were also adapted from the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002). Examples of items include: "It is embarrassing when my symptoms flare up" and "I should be able to control my symptoms".

The brief 8-item *Beliefs about Fatigue Symptoms* (Beliefs-F) scale, developed and validated by Wilson, Salkovskis, & O'Dowd (2015) was used to measure potentially unhelpful beliefs about the negative consequences of activity and fatigue, and somatic attributions for fatigue.

The *Beliefs about Gastrointestinal Symptoms* (Beliefs-G) scale was developed for this study. Items consistent with the CBT model were taken from the Cognitive Scale for Functional Bowel Disorders (CSFBD; Toner et al., 1998) and from CBT-relevant themes in the literature, regarding potentially unhelpful beliefs about the cause, and consequences (functional and social) and management of gastrointestinal symptoms (e.g. Hauser et al., 2014). This resulted in thirteen statements, for example, "I worry about losing control of my bowels in public" and "It's embarrassing when I keep going to the bathroom". For each participants were asked to rate their agreement/disagreement on a 10-point Likert scale.

Behaviour factors associated with physical conditions. No previously validated measures could be identified that specifically evaluated CBT-related behaviours in PPS. Therefore, the 18-item *Physical Symptoms and Behaviour* (Behaviour-P) scale was developed for study. A 10-point agreement/disagreement Likert rating was used for each item. The items were derived from themes in the CBT literature relating to potentially unhelpful

avoidance, withdrawal and safety-seeking (e.g. Deary et al., 2007). For example, “I ask for reassurance about my symptoms” and “I avoid attending social activities because of my symptoms”.

No previously validated measures could be identified that specifically evaluated fatigue-related behaviours. Therefore, a 9-item brief *Fatigue Symptoms and Behaviour* (Behaviour-F) scale was compiled for the present study. Relevant items from the Behavioural Activation for Depression Scale (BADS; Kanter, Mulick, Busch, Berlin, & Martell, 2006) were adapted and other items were derived from behavioural themes in the literature that related to managing fatigue symptoms e.g. withdrawal, avoidance, reduced/increased activity (Surawy et al., 1995). For example, “There were certain things I needed to do that I didn’t do” and “Most of what I did was to escape from or avoid something unpleasant”. For each item, participants were asked to rate the degree to which they agreed or disagreed with a statement using 6–point Likert rating scale.

The Irritable Bowel Syndrome Behavioural Responses Questionnaire (IBS-BR; Reme et al., 2010) was adapted for this study and referred to as the *Gastrointestinal Problems and Behaviours* (Behaviour-G) scale. Items from the IBS-BR that were consistent with the CBT model were retained (e.g. potentially unhelpful avoidance, withdrawal and safety seeking behaviours to manage gastrointestinal symptoms were included). This resulted in 16 statements, for example, “After opening my bowels I check my stool for abnormalities” and “I wear baggy clothing when my stomach feels bloated or distended”. For each item, participants rated their agreement/disagreement using a 7–point Likert rating scale.

Analysis

Overview of Analytical Procedure

The groups (CFS/ME only, IBS only, comorbid and HC) were first compared in terms of demographic characteristics using a one-way Analysis of Variance (ANOVA) for age. For categorical variables, Chi-Square analyses were completed or percentages are provided. The general psychological characteristics of the groups were then compared using One Way ANOVAs.

The primary analysis focused on whether CFS/ME, IBS and HC groups were similar or different in terms of their beliefs about symptoms. Firstly, the psychometric properties of the belief scales (Beliefs-P, Beliefs-F and Beliefs-G) were investigated. Following this, a 3x3 mixed model ANOVA was used to analyse mean scores on the belief scales across groups (means per item were used to ensure comparability, given the different number of items in the scales).

A secondary analysis explored whether these three groups were comparable with regard to behavioural responses to symptoms. The psychometric properties of the behaviour scales (Behaviour-P, Behaviour-F and Behaviour-G) were evaluated. This was then followed by a 3x3 Mixed Model ANOVA analysing mean scores on the behaviour scales across groups.

The tertiary analysis incorporated the comorbid group to evaluate the extent to which this group shared cognitive and behavioural characteristics with the single diagnostic groups and whether there was any evidence of interaction between these problems when they co-occur. Two 4x3 Mixed Model ANOVAs were used to analysis mean scores on belief scales and behaviour scales.

Inspection of histograms, p-plots and boxplots showed acceptable levels of normal distribution and minimal outliers on all measures. Mauchley's Test of Sphericity was completed for repeated measures analyses to evaluate serial dependency; where present, the Epsilon co-efficient was used to generate Greenhouse-Geisser estimates. Throughout, where, post-hoc analyses were performed and Homogeneity of Variance (HOV) assumptions were met Fisher's Least Significance Difference (LSD) was used. In cases where it was not met Dunnett's T3 was used. Data was analysed using SPSS (v22.0.0.0, Chicago, IL). Cases with one or more missing values on a variable being analysed were eliminated by default (i.e. SPSS listwise missing value deletion).

Results

Demographic Characteristics

Demographic characteristics of the groups are presented in Table 1. There were no significant differences between the groups in terms of age, sex,

relationship status and level of education attainment. However, more people in the CFS/ME and comorbid group were unemployed than the other groups. In addition, less ethnic diversity was seen in the IBS & HC group.

Table 1

Sample demographics

Demographics	CFS/ME (n = 21)	IBS (n = 40)	Comorbid CFS/IBS (n = 17)	Healthy Control (n = 65)	ANOVA/ Chi-Square
Age:	*M*=33.52 *SD*=8.26	*M*=33.46 *SD*=9.85	*M*=34.94 *SD* =8.66	*M* = 31.6 *SD*=12.72	$F_{(3,141)}$=.553, *p* = .65
Sex:					
Female	85.7%	92.5%	82.4%	73.8%	$\chi^2_{(3, N=143)}$ = 6.06, *p* = .11
Male	14.3%	7.5%	17.6%	26.2%	
Ethnicity:					
Caucasian	85.7%	100%	100%	93.8%	
Other	14.3%	0%	0%	6.2%	
Relationship:					
Married	45%	47.5%	41.2%	41.55%	$\chi^2_{(3, N=142)}$ = .42, *p* = .94
Not married	55%	52.5%	58.8%	58.5%	
Employment:					
Employed (or education)	65%	92.5%	76.5%	96.9%	
Not employed	35%	7.5%	23.5%	3.1%	
Education level:					
GCSE/A levels	28.6%	20%	52.9%	38.5%	$\chi^2_{(6, N=143)}$ = 7.82, *p* = .25
Undergraduate	38.1%	45%	17.6%	32.3%	
Postgraduate	33.3%	35%	29.4%	29.2%	

* Insufficient numbers in this category to complete Chi Square analysis, please refer to percentages.

General Psychological Characteristics

Using one-way ANOVAs, significant main effects were found between the groups on the PHQ-9 ($F_{(3,142)}$ = 32.28, *p* < .001), the GAD-7 ($F_{(3,141)}$ = 67.12, *p* < .001), the SHAI-14 ($F_{(3,140)}$= 11.256, *p* < .001), the WASA ($F_{(3,142)}$ = 8.74, *p* <

.001) and the MD ($F_{(3,139)}$= 26.24, p < .001). HOV assumption was met for all of the measures. Mean scores and Standard Deviations are outlined in Table 2. Post hoc analysis showed that the clinical groups (CFS/ME, IBS, comorbid) scored significantly higher than HCs on all measures. The clinical groups did not significantly differ from each other on the anxiety measures (GAD-7 and SHAI-14). The CFS/ME and the co-morbid groups scored significantly higher than the IBS group on the PHQ-9, WASA and the MD, but they were not significantly different from each other (see Appendix F for further details).

Table 2

Sample general psychological characteristics

Measure	CFS/ME	IBS	Comorbid	HC
	n = 21	*n = 40*	*n = 17*	*n = 65*
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
PHQ-9	n = 21	n = 40	n = 17	n = 65
	12.76 (5.37)[a]	5.4 (3.98)[b]	11.23 (5.47)[a]	3.65 (3.71)
GAD-7	n = 21	n = 40	n = 17	n = 65
	7.6 (5.23)[a]	6.45 (4.79)[a]	7.24 (4.68)[a]	3.29 (3.56)
SHAI-14	n = 21	n = 39	n = 17	n = 64
	15.86 (7.69)[a]	14 (6.89)[a]	14.71 (5.28)[a]	8.6 (5.53)
WSAS	n = 21	n = 40	n = 17	n = 64
	25.14 (9.45)[a]	10.15 (7.78)[b]	20.59 (10.03)[a]	2.09 (5.03)
MD	n = 21	n = 39	n = 17	n = 63
	32.1 (21.2)[a]	12.71 (13.9)[b]	31.7 (23.29)[a]	4.92 (9.08)

[a,b,c] Those scores sharing a superscript do not significantly differ from each other (p > 0.05)

Belief Scales

Psychometric properties. First, the internal consistency (Cronbach's alpha) of the three beliefs scales was calculated for the groups as a whole and separately (see Table 3).

Table 3:

Internal consistency (Cronbach's alpha) for belief scales

Scale (No. of items)	CFS/ME (n = 21)	IBS (n = 40)	Comorbid CFS/IBS (n = 17)	HC (n = 65)	Whole sample (n = 143)
Belief-P (22)	.79	.82	.77	.96	.94
	(n = 20)	(n = 39)	(n = 17)	(n = 57)	(n = 133)
Belief-F (8)	.67	.7	.77	.86	.85
	(n = 21)	(n = 36)	(n = 17)	(n = 61)	(n = 135)
Belief-G (13)	.93	.93	.87	.94	.94
	(n = 15)	(n = 37)	(n = 17)	(n = 61)	(n = 143)

Primary analyses. Following this, a 3x3 Mixed Model ANOVA was completed with the three belief scales as the within subjects factors and the CFS, IBS and HC groups as the between-subjects factors. Box's Test was not significant, indicating the assumption of equality of covariance matrices was met. Mauchley's Test of Sphericity was significant and, hence, the Greenhouse-Geisser estimate was used. A significant main effect was not found for the within subject factor (beliefs scales), $F_{(1.69,\ 164.17)} = 2.41$, $p = .1$, $\eta_p^2 = .02$. A significant main effect was found for group, $F_{(2,\ 97)} = 23.64$, $p < .001$, $\eta_p^2 = .33$. This was modified by a significant interaction, $F_{(3.39,\ 164.17)} = 16.06$, $p < .001$, $\eta_p^2 = .25$. This interaction is represented in *Figure 2.*

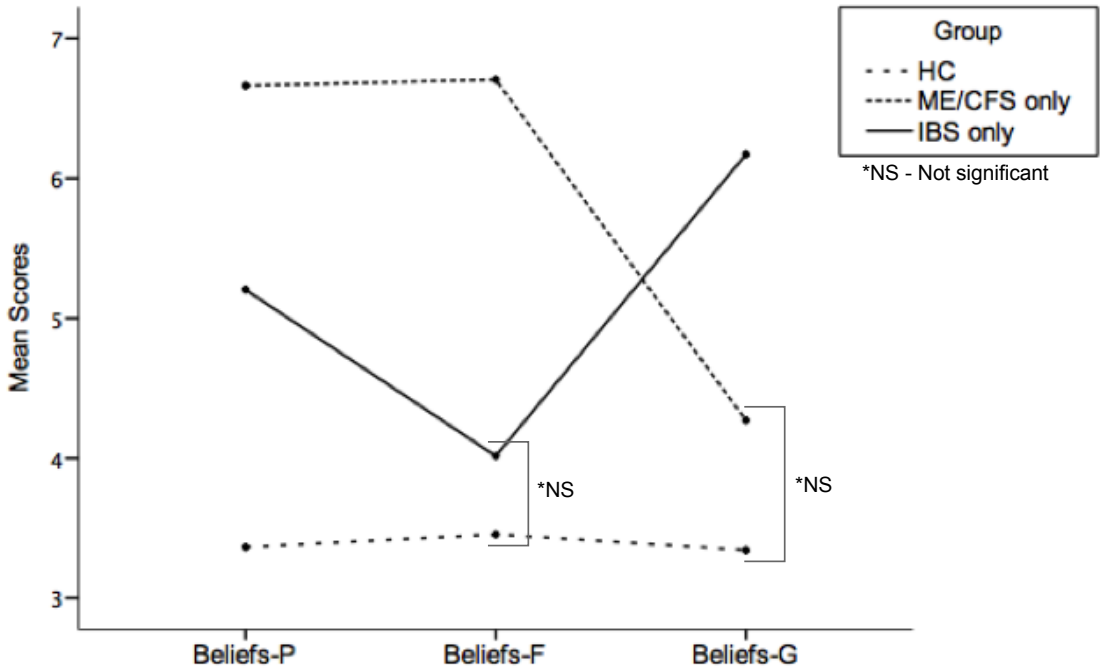

Figure 2. Mean belief scores by group (CFS/ME, IBS and HCs)

In order to understand the nature of this interaction, a simple main effects analysis was used. A significant group effect was found for Belief-P ($F_{(2, 115)}$= 32.46, p < .001, η_p^2 = .37), Belief-F ($F_{(2, 117)}$= 20.09, p < .001, η_p^2 = .26) and Belief-G ($F_{(2, 112)}$=15.86, p < .001, η_p^2 = .22). HOV was not met for the Belief-P or Belief-F scales but was met for the Belief-G scale. Hence, for multiple comparisons, Dunnet's T3 was used for the former and Fisher's LSD for the latter. Mean belief scores and standard deviations for each group are presented in Table 4. On the Belief-P scale (i.e. transdiagnostic beliefs) the HC group were significantly lower than both the CFS/ME (p < .001) and the IBS (p < .001) groups. In addition, the CFS/ME group was significantly higher than the IBS group (p < .001). In terms of the Belief-F scale (i.e. disorder-specific fatigue beliefs), the CFS/ME group was significantly higher than the IBS (p < .001) and HC (p < .001) groups, who did not significantly differ from each other (p = .18). With regard to the Belief-G scale (i.e. the disorder-specific gastrointestinal beliefs), the IBS group was significantly higher than the CFS/ME (p = .01) and HC (p < .001) groups, but they did not significantly differ from each other (p = .67).

Table 4

CFS/ME, IBS and HC groups' mean and standard deviations on belief measures

Belief Scales	CFS/ME	IBS	HC
	n = 14	*n = 32*	n = 54
	M (SD)	*M (SD)*	*M (SD)*
Beliefs-P	6.66 (1.31)[a]	5.2 (1.21)[b]	3.36 (1.95)[c]
Beliefs-F	6.71 (1.42)	4.02 (1.35)[a]	3.46 (1.93)[a]
Beliefs-G	4.27 (2.31)[a]	6.17 (2.19)	3.34 (2.21)[a]

[a,b,c] Those scores sharing a superscript do not significantly differ from each other (p>0.05)

Behaviour Scales

Psychometric properties. The internal consistency (Cronbach's alpha) of the three behaviour scales was calculated for the groups as a whole and separately (see Table 5).

Table 5

Internal consistency (Cronbach's alpha) for behaviour scales

Scale	CFS/ME	IBS	Comorbid CFS/IBS	HC	Whole sample
(No. of items)	(n = 21)	(n = 40)	(n = 17)	(n = 65)	(n = 143)
Behaviour-P (18)	.83	.88	.83	.93	.92
	(n = 21)	(n = 37)	(n = 16)	(n = 60)	(n = 134)
Behaviour-F (9)	.58	.86	.83	.78	.81
	(n = 21)	(n = 38)	(n = 17)	(n = 60)	(n = 136)
Behaviour-G (16)	.94	.81	.85	.92	.92
	(n = 14)	(n = 40)	(n = 17)	(n = 62)	(n = 133)

Secondary analyses. A 3x3 Mixed Model ANOVA was then completed with the three behaviour scales as the within subjects factors and the CFS, IBS and HC groups as the between-subjects factors. The assumptions of equality of covariance matrices and sphericity were met for all behaviour related analyses.

A significant within subject main effect was found for behaviour scales, $F_{(2,206)}$ = 103.97, p < .001, η_p^2 = .5. A significant main effect was found for group, $F_{(2,103)}$ = 20.65, p < .001, η_p^2 = .29. This was modified by a significant interaction, $F_{(4,206)}$ = 15.2, p < .001, η_p^2 =.23. This interaction is represented in *Figure 2.*

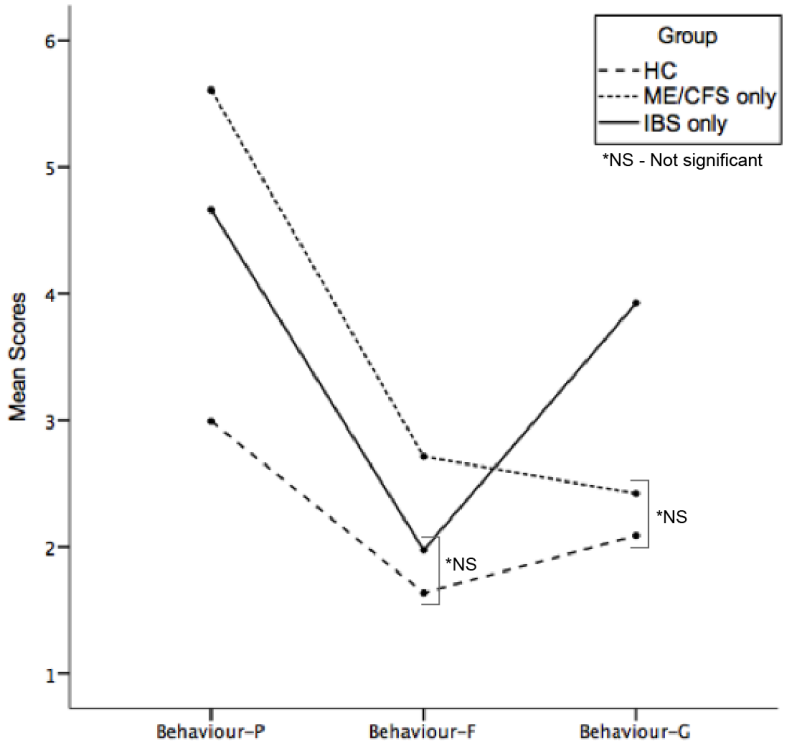

Figure 3. Mean behaviour scores by group (CFS/ME, IBS and HCs)

Simple main effects were completed to explore the interaction. A significant group effect was found for Behaviour-P ($F_{(2, 117)}$ = 23.96, p < .001, η_p^2 = .3), Behaviour-F ($F_{(2, 118)}$ = 8.57, p < .001, η_p^2 = .13) and Behaviour-G ($F_{(2, 115)}$ = 31.13, p < .001, η_p^2 = .36). HOV was met for all behaviour scales and Fisher's LSD was used. On the Behaviour-P scale (i.e. transdiagnostic behaviour) the HC group were significantly lower than both the CFS/ME (p < .001) and the IBS (p < .001) groups. In addition, the CFS/ME group was significantly higher than the IBS group (p = .02). The CFS/ME group was also significantly higher than the IBS (p < .05) and HC (p < .001) groups on the Behaviour-F scale (i.e. disorder-specific fatigue behaviour). The IBS and HC groups scores did not significantly differ on the fatigue behaviour scale (p = .31). Similarly, the IBS

group was significantly higher than the CFS/ME ($p < .001$) and HC ($p < .001$) groups on the Behaviour-G scale (i.e. the disorder-specific gastrointestinal beliefs). The CFS/ME and HC groups did not significantly differ ($p = .38$). Mean behaviour scores and standard deviations for each group are presented in Table 6.

Table 6

CFS/ME, IBS and HC groups' mean and standard deviations on behaviour measures

Behaviour Scales	CFS/ME	IBS	HC
	n = 14	n = 35	n = 57
	M (SD)	*M (SD)*	*M (SD)*
Behaviour-P	5.61 (1.48)[a]	4.66 (1.57)[b]	2.99 (1.84)[c]
Behaviour-F	2.71 (.9)	1.97 (1.1)[a]	1.64 (1.01)[a]
Behaviour-G	2.42 (1.48)[a]	3.93 (1.04)	2.09 (1.12)[a]

[a,b,c] Those scores sharing a superscript do not significantly differ from each other ($p>0.05$)

Tertiary Analyses

Although we had not sought to recruit people who were co-morbid, a reasonable number were identified. Therefore, the primary and secondary analyses regarding beliefs and behaviours were repeated with the co-morbid group included (see Appendix G for details). Consistently, a significant main effect was found for group on both the beliefs and behaviours scales. On both counts a significant interaction was found. Mean scores and standard deviations for each group are presented in Table 7. Multiple comparisons indicate that on disorder-specific measures the co-morbid group showed characteristics of both CFS/ME and IBS. In relation to transdiagnostic measures the co-morbid group's scores were most similar to the CFS/ME group.

Table 7

CFS/ME, IBS, co-morbid and HC groups' mean and standard deviations on behaviour measures

Scales	CFS/ME	IBS	Co-morbid	HC
	n = 21	*n = 40*	*n = 17*	*n = 65*
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*
Beliefs-P	n = 14	n = 32	n = 17	n = 54
	6.66 (1.31)[a]	5.2 (1.21)[b]	6.32 (1.1) [a]	3.36 (1.95)[c]
Beliefs-F	6.71 (1.42)[b]	4.02 (1.35)[a]	6.1 (1.19)[b]	3.46 (1.93)[a]
Beliefs-G	4.27 (2.31)[a]	6.17 (2.19)[b]	5.82 (1.8) [b]	3.34 (2.1)[a]
Behaviour-P	n = 14	n = 35	n = 16	n = 57
	5.61 (1.48)[a]	4.66 (1.57)[b]	5.8 (1.51)[a]	2.99 (1.84)[c]
Behaviour-F	2.71 (.9)[b]	1.97 (1.1)[a]	2.58 (1.17)[b]	1.64 (1.01)[a]
Behaviour-G	2.42 (1.48)[a]	3.93 (1.01)[b]	3.76 (1.12)[b]	2.09 (1.12)[a]

[a,b,c] Those scores sharing a superscript do not significantly differ from each other (p>0.05)

Discussion

Overview

The aim of the present study was to compare people with CFS/ME and IBS, regarding their beliefs about symptoms and behavioural responses to them, to establish the extent of similarities and differences. Although the clinical groups were comparable in anxiety (generalised and health), the CFS/ME and co-morbid groups scored significantly higher in depression, functional impairment and mental defeat. The clinical groups scored significantly higher than the benchmarking group of HCs on all of these measures. The main belief and behaviour measures were divided into general and symptom specific ratings to evaluate the contribution of both transdiagnostic and symptom-specific factors. As expected both groups scored higher than HCs in terms of transdiagnostic beliefs and behaviours; but the CFS/ME and co-morbid groups also scored significantly higher than the IBS group. In addition, the CFS/ME group endorsed more fatigue-specific beliefs and behaviours related to fatigue, while the IBS group scored higher on disorder-specific characteristics relevant to gastrointestinal symptoms.

Previous research

The main contribution of this study is that it directly compared people with CFS/ME and IBS in terms of their beliefs about symptoms and behavioural responses to symptoms. Previous research has considered cognitive-behavioural factors in PPS generally, and CFS/ME and IBS separately, and these studies' findings can be considered in this context. For instance, empirical studies (see Deary et al., 2007) have shown that beliefs (e.g. about the cause, consequence and management of symptoms) and behaviours (e.g. withdrawal, avoidance and safety-seeking) are involved in the maintenance of PPS generally, which is consistent with this study's findings that all clinical groups endorsed more transdiagnostic items concerning these factors than healthy controls. Given the high co-morbidity found between CFS/ME and IBS (Hamilton et al., 2009) it is arguably not surprising that common factors were identified.

In addition, to these *commonalities*, the CFS/ME and IBS groups each had *distinctive* cognitive and behavioural profiles. For instance, the CFS/ME and co-morbid group endorsed more disorder-specific beliefs and behaviours relating to fatigue than the IBS or healthy control group. The belief (e.g. about harmfulness of activity, loss of performance) and behaviour (e.g. activity avoidance, withdrawal) items endorsed by the CFS/ME and co-morbid groups corresponded with factors that have been included in the empirically supported disorder-specific CBT model for CFS/ME (Knoop et al., 2010; Surawy et al., 1995; Vercoulen et al., 1997). This study's finding that neither the IBS group nor the health control group shared these beliefs and behaviours supports the view that they are specific to CFS/ME.

Similarly, IBS and co-morbid groups endorsed the beliefs (e.g. catastrophic interpretation regarding social and functional consequences) and behaviours (e.g. avoidance of social situations, checking stools) that are relevant to gastrointestinal symptoms, but the CFS/ME or health control groups did not. Again, this indicates that these factors are specific to IBS. While not previously compared to CFS/ME, empirical studies have found that people with IBS have more of these beliefs and behaviours than healthy controls or people

with other organic gastrointestinal problems (Gibbs-Gallagher et al., 2001; Hunt et al., 2009; Posserud et al., 2009). Hence, the factors identified in the study are consistent with those included in disorder-specific CBT models for IBS (Hauser et al., 2014; Kennedy et al., 2012; Lackner, 2005).

Overall, these findings indicate that there are both similar and different beliefs and behaviours in CFS/ME and IBS. The presence of these transdiagnostic and disorder-specific features is comparable with what is found in other emotional disorders (e.g. anxiety, depression), thus implying that the content-specificity hypothesis (Beck, 1976) is also relevant in PPS. While this is promising, future research should seek to explain the exact mechanism by which these factors interact to form the 'vicious cycles' that maintain symptoms. It may be helpful to draw from experimental studies, which were used to demonstrate the interactional role of similar factors in depression (Moorey, 2010) and anxiety (Salkovskis, 1996). Additionally, beliefs regarding the unacceptability of emotions has been linked to both CFS/ME and IBS previously but was not considered here (Bowers & Wroe, 2016; Rimes & Chalder, 2010). Hence, studies seeking to replicate these findings should also consider including a measure for these beliefs. On this note, it was beyond the scope of this study to consider the full range of possible factors (cognitive, behavioural, emotional, social, physiological) but if coherent CBT maintenance models are to be developed these factors also need to be included in future research.

Limitations

When considering the implications of these findings, it is important to note some of the limitations regarding the sample. The study was slightly underpowered, as power analysis indicated a sample size of 33 in each group was needed. Additionally, whilst some of the CFS/ME group was identified through clinical services, most of the sample was recruited through the community (i.e. online social media) and it is not possible to guarantee the results would be the same for individuals who seek treatment. Another limitation of community recruitment was that it relied on participants to self-identify as having CFS/ME or IBS and it was not possible to verify that this has been confirmed by clinician diagnosis. This was addressed by applying clinical cut-offs on well-validated measures for CFS/ME (i.e. CF-Scale; Cella & Chalder,

2010; Chalder et al., 1993) and IBS (i.e. IBS-SSS; Francis et al., 1997). However, some participants met caseness for a group (CFS/ME, IBS or co-morbid) but had not self-identified as belonging to that group. Hence, to ensure the groups were distinct, those who scored more than two standard deviations on the CF-Scale or IBS-SSS but not had not self-identified as having CFS/ME or IBS respectively, were removed. A further issue is that the IBS-SSS is based on the ROME I criteria for IBS. While this may mean there is some discrepancy between this study's categorisation and others that have use the updated ROME III criteria, comparative studies have shown that the updates have limited impact on detection of IBS cases (Spiller et al., 2007). Nevertheless, replication with larger samples, with a confirmed clinician diagnosis, is warranted.

The PHQ-9 and GAD-7 were used to screen for depression and anxiety, respectively. Although they are currently the recommended measures for people with CFS/ME and IBS (Improving Access to Psychological Therapies [IAPT], 2012), their validity for these populations is questionable given that they include items relating to the somatic symptoms of depression and anxiety that may overlap with the physical symptoms of these conditions (Cosco, Doyle, Ward, & McGee, 2012). Unfortunately, there remains a lack of appropriately validated alternative measures.

Additionally, the Beliefs-P, Beliefs-G, Behaviour-P, Behaviour-F and Behaviour-G were novel measures that were developed for this study as no standardised measures were identified that targeted the cognitive-behaviour factors of interest. Items consistent with the CBT model were adapted from other validated measures and items were drawn from themes identified in the literature. In hindsight, the phrasing of the questionnaires may be measuring the presence or absence of physical symptoms themselves (e.g. *my fatigue problems* are caused by over-activity) rather than the beliefs and behaviours resulting from them. Future research is advised to consider re-phrasing the items (e.g. *if you experienced fatigue problems* how strongly would you agree that they are caused by over-activity). With the current sample, each measure showed good internal consistency. In addition, the Beliefs-F has only been used in one previous study but had internal reliability in their sample. There is a need

to replicate the psychometric properties of all of these measures using larger samples. Additionally, this study used a cross-sectional design and relied on self-report measures. Longitudinal studies should be used to investigate whether beliefs and behaviours remain stable over time. Also, this study's findings could be expanded with the use of experimental studies to understand the relationship between factors in CFS/ME and IBS further.

Summary and clinical implications

Focusing exclusively on psychological characteristics as a means of explaining the onset and persistence of distressing and debilitating physical symptoms is understandably unacceptable to those experiencing them. This study did not take this stance; rather it recognised that a complex range of interacting physical, cognitive, emotional and behavioural factors have been linked with CFS/ME and IBS and are particularly relevant to quality of life and the experience of disability. Hence, understanding the psychological factors involved is one essential part of developing comprehensive treatments. This study contributes to this by investigating the beliefs about symptoms and behavioural responses to them that has been identified as important in the maintenance and exacerbation of symptoms.

To the author's knowledge, this is the first study to investigate and identify that there are transdiagnostic and disorder-specific beliefs and behaviours in these two groups. Replication studies are required, and other studies should investigate whether the same findings are found in other PPS disorders. Nevertheless, overall these findings support the view that there is significant overlap between PPS disorders but it is by no means complete (Aaron & Buchwald, 2001). Therefore, the findings suggest that it may be appropriate to use a modular transdiagnostic CBT approach for these conditions, and possibly other PPS conditions (Salkovskis et al., in press). Hence, studies evaluating its effectiveness are warranted.

Conflict of interest

The author has IBS and has clinically worked with people experiencing both CFS/ME and IBS symptoms, using CBT. Whilst the author has an invested interest in this area, it is not believed to have impacted the integrity of the

findings. If it had any effect it was most likely that it allowed for more in-depth consideration of how the study's design, methods and findings may be received by people with personal experience of PPS.

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Service Improvement Project

Evaluating & Improving OCD-UK's Conference: Collaboration Between People with Personal Experience and Professionals

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Evaluating & Improving OCD-UK's Conference: Collaboration Between People with Personal Experience and Professionals

Abstract

People with mental health problems in general and Obsessive Compulsive Disorder (OCD) in particular often delay seeking help and lack information about evidence-based treatment. Provision of such information has increasingly become a task led by third sector organisations. OCD-UK is a charity, led by people with personal experience of OCD that runs an annual conference to address these issues. It primarily aims to promote understanding of OCD and its treatment, and increase optimism regarding the ability to overcome OCD. It also aims to highlight the need for psychological treatment, specifically Cognitive Behavioural Therapy. The present study undertook a systematic evaluation of OCD-UK's 2014 conference. Sufferers (n=50) and carers (n=41) completed questionnaires pre- and post-conference. Changes in their scores showed that the conference was successful in increasing attendees' confidence in their understanding of OCD and knowledge of treatment options. Additionally, the following beliefs weakened: pessimism about the ability to overcome OCD and perception of OCD as a biological illness. Beliefs about perceived need for psychological therapy to overcome OCD strengthened. Generally, sufferers and carers did not differ in terms of the impact of the conference. The findings illustrate the value of third-sector organisations, like OCD-UK, in providing information and addressing beliefs that are considered barriers to accessing treatment. The implications of these findings are discussed, along with recommendations for future research.

Key words: Obsessive-Compulsive Disorder (OCD), Cognitive Behavioural Therapy (CBT), service-user, personal experience and evaluation.

Highlights:

- OCD-UK runs annual conferences to promote understanding of OCD and how to overcome it.
- The conference is effective in increasing attendees' confidence in their knowledge of OCD.

- Attendees' pessimism about ability to overcome OCD and their perception of OCD as a biological illness weakened pre to post conference.
- Attendees' belief in the need for psychological therapy to overcome OCD strengthened pre to post conference.

Evaluating & Improving OCD-UK's Conference: Collaboration Between People with Personal Experience and Professionals

Introduction

Background

In the UK, third sector (charity) organisations such as MIND and Rethink provide significant support for people with mental health problems, and their family and friends. Both of these organisations are managed and run by both people with personal experience of mental health problems and professionals. The present study focuses on the work of OCD-UK, which is a registered charity run entirely by people with personal experience of Obsessive Compulsive Disorder (OCD), including sufferers and carers. It envisions a time when everyone affected by OCD will receive the highest quality evidence-based care (OCD-UK, 2015) as quickly as possible. While OCD-UK consults with professionals to realise this vision, it remains service-user led. OCD-UK facilitates online discussion forums, provides a telephone and e-mail advice line, facilitates support groups, publishes information materials, actively supports ethical research in OCD and lobbies policymakers to improve treatment.

Additionally, OCD-UK holds an annual conference to help people increase their understanding of OCD and its treatment. The conference is provided for sufferers and carers, with an estimated even split of attendees. OCD-UK recognised the important role carers provide in supporting those with OCD and therefore aimed to increase both sufferers and carers' confidence in their understanding of OCD and its treatment, as well as to increase their optimism regarding ability to overcome OCD. Secondary aims were to reduce the perception of OCD as an exclusively a biological illness and rather support the cognitive-behavioural conceptualisation of OCD and highlight the need for psychological therapy to overcome it.

Professionals with expertise in OCD treatment are invited to speak about research findings and good evidence-based practice. Sufferers and their families and friends are also invited to speak about their personal experiences of OCD and its treatment. Previous conferences have been well attended (with

approximately 150 attendees each year) and responses on feedback forms have consistently been positive. However, conference organisers recognised that these forms do not provide sufficient information to determine whether the conference's aim to increase attendees' understanding of OCD and its treatment has been met.

For these reasons, OCD-UK expressed an interest in working alongside the University of Bath's Clinical Psychology Programme on a project to evaluate and improve its conferences. This project offered an opportunity for meaningful collaboration between people who are experts in OCD through personal experience and professionals with expertise in service evaluation and improvement.

Relevant Literature

Psychological understanding of OCD. OCD is characterised by recurrent and distressing thoughts, impulses or images (obsessions) and repetitive behavioural or mental acts (compulsions; American Psychiatric Association [APA], 2013). In the past, biological and Freudian theories of OCD have been proposed but the effectiveness of treatments based on either of these theories has been limited (Stobie, 2009). Hence, OCD was often considered a 'difficult to treat' disorder, with a chronic course, poor outcomes and high relapse rates (Eisen et al., 2013; Steketee, Eisen, Dyck, Warshaw, & Rasmussen, 1999).

However, over the last 35 years, the perceived treatability of OCD has gradually improved following the development of behavioural and cognitive theories of OCD. Behavioural theories (Meyer, 1966; Rachman, Hodgson, & Marks, 1971; Rachman, Marks, & Hodgson, 1973) are based on the understanding that obsessions are neutral stimuli that have become associated with anxiety (classical conditioning) and compulsions reduce the anxiety associated with intrusions in the short-term, but in the longer term maintain anxiety (negative reinforcement). Hence, in treatment sufferers are required to expose themselves to conditions that would usually elicit obsessions without performing compulsions until their anxiety levels habituate. This is referred to as Exposure Response Prevention (ERP).

Cognitive theories were developed, following Rachman & De Silva's (1978) findings that intrusive thoughts, images and impulses are a normal occurrence within the general population. Hence, it is not the occurrence of these thoughts, images and impulses but the interpretation of them as threatening that leads to obsessional thinking (Salkovskis & Warwick, 1985; Salkovskis, 1985, 1999). Specifically, research indicates that they are interpreted as meaning the individual is responsible for harm or its prevention (Salkovskis, 1999). Cognitive therapy focuses on supporting the individual to develop a less threatening explanation. ERP techniques are still used but their main purpose is to test out these explanations rather than anxiety habituation (i.e. behavioural experiments) (Salkovskis, 1999).

Barriers to accessing evidence based treatment. Cognitive-behavioural therapy (CBT) that incorporates ERP -based on either the behavioural or cognitive approach- is the recommended treatment for OCD (National Institute for Health & Clinical Excellence [NICE], 2006). There is evidence, however, that most people suffering from OCD consistently delay seeking help for several years, which is concerning given that treatment delay is associated with severity and poorer outcomes (García-Soriano, Rufer, Delsignore, & Weidt, 2014; Glazier, Calixte, Rothschild, & Pinto, 2013). When treatment is first offered, it is seldom CBT; even when it is offered as CBT, as it frequently does not meet minimum criteria for adequacy (Stobie, Taylor, Quigley, Ewing, & Salkovskis, 2007). We therefore need to address two questions: firstly, why do people delay for so long and secondly why is substandard treatment so frequently offered and accepted. Better understanding of these questions should lead to more rapid access to treatment and better outcomes.

OCD sufferers can find it difficult to access treatment because of shame and fears of the consequences of seeking help. Unfortunately, stigma surrounding mental health problems remains (Torres et al., 2006). Sufferers may have fears about how family, friends and employers will respond to them having a mental illness. Marques et al.'s (2010) online Barriers to Treatment Questionnaire found that in a sample of 175 participants with OCD the most

frequently endorsed reason for not seeking treatments was 'I felt ashamed of needing help for my problem' (58%).

Lack of information regarding OCD has also been proposed as a barrier to accessing treatment. For example, Torres et al. (2007) argue that public awareness of OCD is low, especially when compared with depression. Sufferers and their family and friends may not recognise the symptoms of OCD (Stengler-Wenzke, Trosbach, Dietrich, & Angermeyer, 2004). Equally, carers may be unaware that they are playing a role in the maintenance of OCD symptoms through the provision of reassurance and accommodation of compulsions (Thompson-Hollands, Edson, Tompson, & Comer, 2014).

In particular, it is possible that sufferers and carers have not been informed of the CBT conceptualisations of OCD. Research indicates that people often hold biological explanations for psychological problems generally and OCD specifically (Cottraux et al., 1993; Lax, Basoglu, & Marks, 1992; Lebowtiz, 2014). Consequently, they place less value on psychological interventions and are more likely to request medication based treatments (Cottraux et al., 1993; Laz et al., 1992; Lebowtiz, 2014).

Generally, not possessing information about the treatment itself and how to access are known barriers to help seeking. Goodwin et al. (2002) found that in their sample of 1,241 people who met the criteria for OCD and had not sought treatment, a lack of information regarding where to go for treatment was the most commonly endorsed reason for this (39.8%), followed by beliefs that they could handle it on their own (28.4%). Beliefs regarding the ineffectiveness of OCD treatment and concerns about speaking with health care professionals about difficulties have also been identified as barriers to seeking treatment (Marques et al., 2010; Williams, Domanico, Marques, Leblanc, & Turkheimer, 2012). In particular, people with OCD who experience intrusive thoughts with sexual, violent and death related content may fear how professionals will respond e.g. subjection to lengthy and inappropriate risk assessments (Veale, Freeston, Krebs, Heyman, & Salkovskis, 2009).

Most of the studies outlined above have been survey based. The authors are aware of one qualitative study, conducted by a researcher with personal experience of OCD, which explored help-seeking in a sample of 17 people with OCD (Robinson, Rose, & Salkovskis, in press). They found similar barriers to seeking treatment as those reported above: stigma; personal beliefs around perceived need for treatment; lack of knowledge about OCD among sufferers and their partners and family; and concerns regarding professionals' reactions. Interestingly, a number of help-seeking enablers were also identified: being supported by partners, family, and others with personal experience of OCD to seek help; information and personal accounts of OCD in the media; confidence in General Practitioners (GPs); reaching a crisis point; and the nature of intrusive thoughts.

Nevertheless, when sufferers do seek treatment, professionals often fail to recognise symptoms as OCD. In one study, 360 members of the APA gave their diagnostic impressions based on case vignettes and 38.9% of participants failed to identify OCD presentations (Glazier et al., 2013). Furthermore, when OCD is identified sufferers are not guaranteed evidence-based treatment. For instance, Stobie et al. (2007) found that in a sample of 57 OCD sufferers who had accessed treatment but failed to make satisfactory gains, 84% had failed to respond "because the treatment they had been offered was either fundamentally inadequate or inadequately delivered" (p 281). This issue is not isolated to OCD. Shafran et al. (2009) highlighted that people with mental health conditions routinely do not receive the recommended evidence-based treatment or when they supposedly do it is not delivered adequately.

In CBT, inadequate treatment may include an absence of a shared understanding of the problem and corresponding rationale for the treatment, insufficient dose of therapy and an inexperienced therapist. Rachman (1983) helpfully differentiated between a sufferer failing to make improvements for these reasons (technical treatment failure) and failing to make sufficient gains following an adequate treatment that adhered to evidence-based protocols (serious treatment failure). It is highly probable that sufferers, as well as their partners and family, would not have the necessary information to know whether or not the treatment provided was adequate and in keeping with NICE

guidelines. Furthermore, it is unlikely that this distinction is made clear to clients. Instead, clients are given labels of ‘treatment-resistant’ or ‘untreatable’, which have connotations of blame.

Beliefs about OCD and its treatment. The lack of information regarding the CBT conceptualisation of OCD and the difficulties to accessing evidence-based treatment outlined above could potentially lead to the development of unhelpful beliefs about the ability to overcome OCD and the utility of treatment. Abramowitz, Franklin, & Cahilll (2003) made similar observations that OCD “patients come to therapy with a wide range of thoughts and beliefs (some useful and others not so useful) about themselves, psychotherapy, and their disorder”. Stobie's (2009) thesis investigated this further and found that the beliefs held by sufferers (in particular their perceived need for psychological therapy) prior to the commencement of CBT predicted changes in their OCD outcome measures at the end of treatment. VanDyke & Pollard (2005) proposed that outcomes could be improved by identifying and changing beliefs associated with therapy-interfering behaviours prior to starting treatment.

The present study, therefore, considers how third sector organisations, such as OCD-UK, can help to address unhelpful beliefs that act as a barrier to accessing and engaging in treatment and in the way potential service users consider treatment choice. There are a number of possible advantages to this approach. First, these organisations have a wider audience. They provide support to sufferers whether or not they are currently accessing professional services. Garcia et al. (2014) recommended the use of education campaigns to aid detection and help seeking. They emphasised the importance of targeting partners and family, and GPs, in addition to sufferers. Second, they tend to work more intensively with the family and friends of sufferers than traditional professional services. NICE (2006) stated that it is imperative that family and friends’ beliefs be considered, given that they can provide a significant role in supporting sufferers through treatment. Third, their support is predominantly provided by people who have personal experience of OCD. Hearing about the nature of OCD and its treatment from them may have a stronger impact than it would from professionals (NICE, 2006).

Summary

OCD sufferers and their family and friends may hold potentially unhelpful beliefs about the successful treatment of OCD. These beliefs are likely to act as barriers to accessing and engaging in any future treatment. Hence, the OCD-UK conference aims to increase people's confidence in their understanding of OCD and its evidence-based treatment. It is hoped that this will help to address some of the unhelpful beliefs that act as barriers to seeking psychological treatment, such as pessimism about ability to recover and perception of OCD as exclusively a biological condition (Cottraux et al., 1993; Laz et al., 1992; Lebowtiz, 2014). It also hopes that by promoting the CBT conceptualisation of OCD, people will develop helpful beliefs regarding the benefits of psychological therapy.

Aims

The present project aims to:

- Systematically evaluate the 2014 OCD-UK conference, with a particular focus on attendees' confidence and beliefs about OCD and its treatment.
- Review and improve procedures for evaluating conferences.
- Build on collaborative working relationships between OCD-UK, healthcare professionals and researchers.

Hypotheses

We hypothesised that attendees' confidence and belief ratings would change pre to post conference. We were interested in whether or not the conference had a greater impact for one group over the other. We anticipated that this might be the case because personal experience of having OCD, compared with supporting somebody who has it is likely to be different, which might impact the groups' responses to the information shared at the conference. Hence, for each hypothesis we also investigated interaction effects. The specific hypotheses are outlined below.

Confidence ratings. The conference aimed to increase attendees' confidence in the following areas: their understanding of OCD, knowledge of treatment options, their knowledge of treatment evidence, their ability to discuss treatment options with professionals and their ability to discuss treatment

concerns with professionals. Hence, we hypothesised that overall attendees' confidence in those areas would increase pre- to post-conference and there might also be differences in sufferers and carers' ratings.

Belief ratings

Primary hypothesis. Our primary hypothesis regarding beliefs was that attendees' pessimism about the ability to overcome OCD would weaken pre- to post-conference, as this was the attitude the conference was designed to change. We also expected the level of reduction in this belief rating may depend on sufferer/carer group.

Secondary hypotheses. The conference was also designed to reduce the perception of OCD as an exclusively a biological illness and rather support the CBT conceptualisation of OCD and highlight the need for psychological therapy to overcome it. Hence, our secondary hypotheses were that attendees' perception of OCD as a biological illness would weaken and their perceived need to for psychological therapy to overcome OCD would strengthen pre- to post-conference. However, we noted that sufferer/carer group might impact the level of change in these beliefs.

Supplementary questions. We did not hypothesis whether beliefs of perceived poor past therapy and beliefs about poor past progress would strengthen or weaken, as the conference was not particularly intended to address these beliefs. However, we decided to investigate whether beliefs in these areas changed pre- to post-conference as a result of being exposed to information regarding current best practice. We also decided to investigate whether the level of change in these beliefs was dependent on sufferer/carer group.

Method

Consultation

OCD-UK prides itself on being an organisation led by people with personal experience of OCD. The researchers provided consultation whilst preserving this emphasis. In-depth consultation between members of OCD-UK's management team and the research team at the University of Bath was

undertaken, between February 2014 and November 2014, through skype meetings and e-mail contacts.

This also allowed for a review of the previous evaluation procedures, which had involved completion of a feedback questionnaire at the end of the conferences. The questionnaires consisted of Likert scales where attendees were asked to rate the relevance of topics, the quality of presentations and satisfaction with the conference's organisation. It also included a qualitative section for suggested improvements. Strengths of this questionnaire were that it was short (taking approximately 5 minutes to complete), had a high completion rate and was anonymous. However, it provided insufficient information to determine whether or not the conference had met its aims to increase attendees' confidence in their understanding of OCD and its treatment, and to promote helpful beliefs about OCD. Hence, it was agreed that amendments were required.

Any changes or additions proposed by the research team were reviewed and given approval by OCD-UK's management team. Their suggestions were actively sought and incorporated. We agreed to retain a questionnaire methodology, with a mixture of Likert rating scales and open-ended feedback questions. Additionally, a pre-post design was introduced. We agreed to not collect some demographic details, such as age and gender, as OCD-UK informed us that anonymity was important to attendees.

Participants

On 1st November 2014, the conference was attended by 149 people (excluding speakers and OCD-UK volunteers, who did not participate). Attendees paid approximately £40.00 to attend. People, over the age of 18, with personal experience of OCD, were invited to participate. Ninety-two (62%) volunteered to participate: 50 sufferers and 41 carers. Based on OCD-UK's request, participants were not asked to disclose their age or gender. Details of participants' personal experience of OCD and treatment are provided in Table 1. Informed consent was obtained from all participants. This project was reviewed and approved by the Psychology Ethics Department, University of Bath (Project ID 14-164; Appendix I).

Table 1

Participant details

Personal Experience of OCD	**N**
Total participants	91
Sufferers:	50
Not received previous treatment	6
Received previous treatment	44
Medication	33
CBT	40
ERP	19
Systemic	2
Psychodynamic	7
Counselling	24
Other	5
Carers:	41
Parent with child under 18	2
Parent with child over 18	22
Spouse/partner	11
Other family member	2
Friend	1
Other	3

Measures

Participants completed pre- and post-questionnaires (Appendix J). These included the following sections:

Background information. At pre, attendees provided details of their connection to OCD and sufferers provided details of any previous treatment experiences.

Hope & expectations. At pre, attendees completed open-ended questions about their hopes and expectations for the conference

Confidence ratings. At pre and post, attendees completed five Likert rating scales, evaluating their: (i) understanding of OCD; (ii) knowledge of treatment options; (iii) knowledge of treatment evidence base; (iv) ability to discuss treatment options with professionals; and (v) ability to discuss treatment concerns with professionals. The internal consistency of the five Likert confidence subscales was calculated for the sample as a whole (Cronbach's alpha = .85), and separately for sufferers (Cronbach's alpha = .78) and carers (Cronbach's alpha = .83).

Beliefs about OCD & treatment. At pre and post, attendees completed an adapted version of the 21-item OCD Therapy Relevant Beliefs Patient Scale (Stobie, 2009). A factor analysis found that it had five subscales: perceived poor past therapy; pessimism about the ability to overcome OCD; perceived poor past progress; perception of OCD as a biological illness; perceived need for psychological therapy (Stobie, 2009). It was shown to have good test-retest reliability, while being sensitive to change (Stobie 2009). The wording of the original scale was adapted to be suitable for carers (i.e. family and friends), as well as sufferers.

Feedback. At post, attendees completed six Likert rating scales exploring the interest of topics, the quality of presentations, the relevance of topics, confidence in working with professionals, promotion of positive views towards OCD treatment and the welcome they received. Attendees also completed open-ended questions about how the conference met their expectations and their suggestions for improvement. This is part of the routine internal evaluation used by OCD-UK and was not analysed here.

Procedure

At conference commencement, attendees were given the pre- and post-questionnaires, with the same anonymous ID. In addition, attendees were provided with an information sheet and a consent form to complete. The pre-questionnaire was completed at the beginning of the conference. The conference included presentations and workshops, delivered by professionals and individuals with personal experience of OCD, on the following topics: treatment of OCD, OCD-UK members' personal experiences of therapy and

recovery, parenting and OCD, and childhood experiences of OCD. The post-questionnaire was completed at the end of conference. Each questionnaire took approximately 5-10 minutes to complete. They were collected at the end of the day. Attendees also had the option to send completed questionnaires to the research team.

Results

Confidence ratings

Inspection of histograms and boxplots showed acceptable levels of normal distribution and minimal outliers. Changes in confidence levels pre- to post-conference were investigated- for attendees overall, as well as for sufferers and carers separately- using the confidence ratings. A 2x2 mixed model repeated measures analysis of variance (ANOVA) was conducted, with pre/post as the within-subjects variable, sufferer/carer as the between-subjects (group) variable and overall (mean) confidence ratings as the dependent variable. Sufferers' and carers' mean scores pre- to post-conference are provided in Table 2.

A main effect was found pre to post, $F_{(1,78)} = 191.23$, $p < .001$, $\eta_p^2 = .71$ and a between-subjects effect of group (carer/sufferer) was found, $F_{(1,78)} = 20.15$, $p < .001$, $\eta_p^2 = .21$. In addition, the main effects were modified by an interaction, $F_{(1,78)} = 8.34$, $p = .005$, $\eta_p^2 = .1$. This interaction is represented in *Figure 1.*

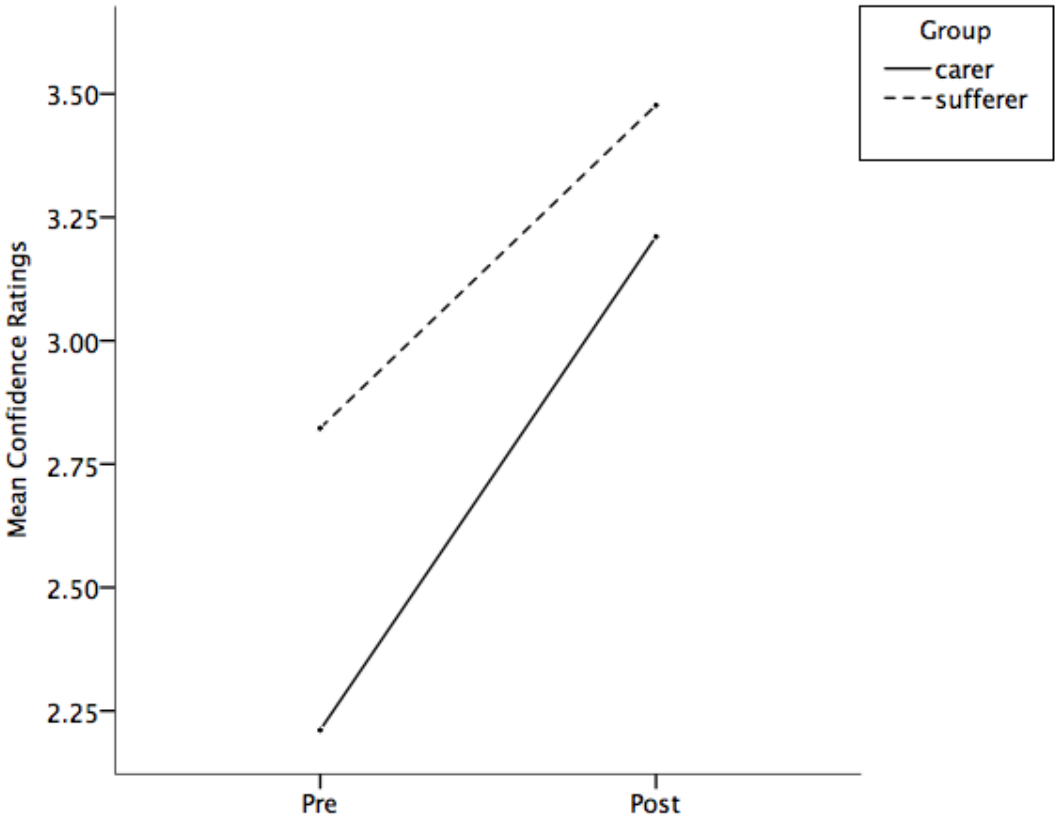

Figure 1. Pre/post mean confidence ratings by group

In order to understand the nature of this interaction, simple main effects analysis was used and the criterion for significance was adjusted to .02 (Bonferroni correction). Results showed that there was a statistically significant difference in sufferers' (M = 2.81, SD = .51, N = 47) and carers' M = 2.26, SD = .61, N = 40) confidence levels pre-conference, $F_{(1,86)} = 20.92$, p < .001, $\eta_p^2 = .2$. A statistically significant difference in sufferers' (M = 3.45, SD = .38, N = 47) and carers' (M = 3.21, SD = .54, N = 36) confidence levels post-conference was found, $F_{(1,83)} = 5.68$, p=.02, $\eta_p^2 = .1$. Lastly, there was a statistically significant difference in the levels of confidence change pre- to post-conference for sufferers (M = -.65, SD = .49, N = 44) and carers (M = -1.00, SD = .58, N = 36), $F_{(1,79)} = 8.34$, p = .005, $\eta_p^2 = .1$. Inspection of the means (Table 2) indicates that over the course of the conference, carers' confidence levels had increased more relative to those of sufferers, starting from a lower baseline and converging post-conference.

Table 2

Sufferers' and carers' confidence scores at pre and post, and their levels of confidence change pre to post

	Pre Conference			Post Conference			Levels of Confidence Change Pre to Post		
	n	*M*	*SD*	N	*M*	*SD*	n	*M*	*SD*
Sufferer	47	2.81	.51	47	3.45	.38	44	-.65	.49
Carer	40	2.26	.61	36	3.21	.54	36	-1	.58
Total	87	2.56	.62	83	3.45	.47	80	-.81	.56

Belief ratings

Changes in the different beliefs scales scores pre- to post-conference were investigated, for attendees overall, as well as for sufferers and carers separately, using the adapted OCD Therapy Relevant Beliefs Patient Scale (Stobie, 2009). Inspection of histograms and boxplots showed acceptable levels of normal distribution and minimal outliers. Five 2x2 mixed model repeated ANOVAs were conducted, with pre/post as the within-subjects variable, sufferer/carer as the between-subjects (group) variable and each belief subscale scores as the dependent variable. For the primary hypothesis regarding pessimism, the criterion for significance was set at .05. To adjust for multiple comparisons for the remainder of the analyses, alpha was adjusted to .01 for the remaining analyses (Bonferroni correction). The results indicated that there were statistically significant main effects in four of the five subscales pre- to post-conference as described below.

Primary hypothesis. A main effect was found pre to post for pessimism about the ability to overcome OCD, $F_{(1,73)} = 91.05$, $p < .001$, $\eta_p^2 = .56$. The main effect of group was not significant $F_{(1,73)} = 2.14$, $p = .15$. This effect was not modified by a suffer/carer group interaction, $F_{(1,73)} = .4$, $p = .53$. Overall this indicated reduced pessimism over the period of the conference regardless of group. Mean scores are provided in Table 3.

Table 3

Sufferer and carer pessimism scores, pre and post conference

	Pre Conference			Post Conference		
	n	*M*	*SD*	n	*M*	*SD*
Sufferer	43	-6.52	21.91	43	-26.59	17.62
Carer	32	-13.59	20.6	32	-31.15	14.42
Total	75	-9.53	21.51	75	-28.53	16.38

Secondary hypotheses. A main effect was found pre to post for perception of OCD as a biological condition, $F_{(1,79)} = 85.76$, $p < .001$, $\eta_p^2 = .52$, indicating there was a statistically significant reduction in scores (Table 4). An overall between-subjects effect for suffer/carer group was not found, $F_{(1,79)} = 1.38$, $p = .24$. These effects were not modified by a suffer/carer group interaction, $F_{(1,79)} = 1.96$, $p = .17$.

Table 4

Sufferer and carer biological scores, pre and post conference

	Pre Conference			Post Conference		
	n	*M*	*SD*	n	*M*	*SD*
Sufferer	45	33.46	18.12	45	12.7	14.9
Carer	36	27.18	17.95	36	11.87	12.76
Total	81	30.67	18.15	81	12.33	13.91

A main effect was found pre to post for perceived need for psychological therapy, $F_{(1,71)} = 33.61$, $p < .001$, $\eta_p^2 = .32$, meaning there was a statistically significant increase in these scores (Table 5). The group main effect (suffer/carer) missed significance on the Bonferroni corrected alpha, $F_{(1,71)} = 4.83$, $p = .03$. There was not a significant interaction, $F_{(1,71)} = .28$, $p = .6$.

Table 5

Sufferer and carer need for psychological therapy scores, pre and post conference

	Pre Conference			Post Conference		
	n	*M*	*SD*	n	*M*	*SD*
Sufferer	43	63.36	17.00	43	74.29	21.71
Carer	30	72.94	17.00	30	82.06	14.66
Total	73	67.30	17.54	73	77.48	19.4

Supplementary questions. A main effect was not found pre to post for perceived poor past therapy, $F_{(1,65)} = 1.09$, p = .3. This indicated that overall attendees' perceptions regarding poor past therapy did not change pre- to post-conference (Table 6). An overall between-subjects effect for suffer/carer group was found, $F_{(1,65)} = 8.6$, p = .005, $\eta_p^2 = .12$, indicating that carers reported higher perceived poor past therapy than sufferers. These effects were not modified by a suffer/carer group interaction, $F_{(1,79)} = 1.96$, p = .17.

Table 6

Sufferer and carer perceived poor past therapy, pre and post conference

	Pre Conference			Post Conference		
	n	*M*	*SD*	n	*M*	*SD*
Sufferer	41	45.24	26.67	41	45.66	25.1
Carer	26	60.18	18.55	26	63.88	21.84
Total	67	51.04	24.35	67	52.73	25.35

A main effect was found pre to post for perceived poor past progress, $F_{(1,72)} = 15.94$, p < .001, $\eta_p^2 = .18$, meaning there was a reduction in poor past therapy scores (Table 7). An overall between subjects effect for suffer/carer group was not found, $F_{(1,72)} = .65$, p = .42,. This effect was not modified by a suffer/carer group interaction, $F_{(1,72)} = 2.49$, p = .12.

Table 7

Sufferer and carer perceived poor past progress, pre and post conference

	Pre Conference			Post Conference		
	n	*M*	*SD*	n	*M*	*SD*
Sufferer	44	49.94	22.98	44	45.4	23.68
Carer	30	48.83	22.79	30	38.36	20.68
Total	74	49.49	22.75	74	42.54	22.64

These results indicate that there was a statistically significant difference in beliefs ratings pre- to post-conference for pessimism about the ability to overcome OCD, with the belief weakening, regardless of sufferer/carer group. There was also a statistically significant weakening of the perception of OCD as a biological condition, regardless of sufferer/carer group. There was a statistically significant strengthening of the perceived need for psychological therapy to overcome OCD, regardless of sufferer/carer group. However, carers' ratings of perceived need for psychological therapy were higher than sufferers' pre and post conference. There was not a statistically significant difference in attendees' perceived poor past therapy scores pre- and post-conference, although carers' scores were higher than sufferers' at pre- and post-conference. Lastly, regardless of group, there was a statistically significant decrease in attendees' perceived poor past progress scores between pre- and post-conference.

Discussion

The aim of this study was to evaluate the OCD-UK conference, focusing on attendees' understanding of OCD and its treatment. Based on confidence ratings pre to post, results found that the conference was successful in increasing sufferers' and carers' confidence in their understanding of OCD, knowledge of treatment options and evidence-base, and ability to discuss treatment options and concerns with professionals. Additionally, the following belief ratings weakened: pessimism about the ability to overcome OCD, the perception of OCD as a biological illness and perceived poor past progress. Beliefs about perceived need for psychological therapy to overcome OCD strengthened. However, beliefs about perceived poor past therapy did not change pre to post for either sufferers or carers.

Previous research identified that OCD sufferers face a number of barriers to accessing and engaging in treatment (Torres et al., 2006). In particular, the barriers of stigma, lack of information regarding OCD and treatment, and concerns regarding the reactions of professionals have been consistently reported (Goodwin et al., 2002; Marques et al., 2010; Robinson et al., in press; Torres et al., 2006). Consequently, this can instil unhelpful beliefs about the treatability of OCD and their ability to overcome it (Abramowitz, Franklin, & Cahill, 2003; Stobie, 2009). VanDyke & Pollard (2005) suggested that these beliefs, which may interfere with therapy be addressed from the outset. This study illustrates how these beliefs can be modified in a cost-effective way by third sector organisations, possibly before they have even presented for treatment or even after previous 'failed' treatments. It is hoped that by developing attendees' confidence in their understanding of OCD and treatment they will be more likely to access treatment and have more positive experiences of it.

Moreover, hearing about the treatability of OCD at the conference, from expert professionals in the field and people who have personal experience of going through it, may be particularly powerful in fostering hope and overcoming stigma. For instance, Robinson et al. (in press) found that having more information about OCD and hearing personal accounts of OCD in the media enables sufferers to seek help. In addition, acquiring information about evidence-based treatments will help sufferers and carers to recognise incidences of 'technical treatment failure' and empower them to request appropriate treatments (Rachman, 1983). Hence, it is hoped that the development of helpful beliefs about the treatability of OCD will contribute to conference attendees having more positive experiences of treatment and professionals going forward.

A further advantage of the OCD-UK conference is that it is also open to the family and friends of people with OCD. It is imperative that family and friends beliefs be considered, given that they can provide a significant role in supporting sufferers through treatment (NICE, 2006). Robinson et al. (in press) found that support from partners and family was an important enabler for

seeking treatment. Contrastingly, partners and family having a lack of information about OCD and treatment was an obstacle to accessing treatment.

In order to fully assess the implications of these findings, it is important to reflect on both the methodological limitations of this study. It included a large sample, with varied experiences of OCD and treatment. However, many were members of OCD-UK and had chosen to pay to attend a large public event. Hence, the generalisability of the findings is limited.

Without baseline and follow-up measurements it is not possible to determine whether the changes in confidence and beliefs are a result of the passage of time, if they are maintained after the conference and whether or not they lead to increased treatment seeking. It was agreed with OCD-UK that asking attendees to complete measures at four time points (baseline, pre, post and follow-up) would be too taxing. However, for future conferences it would be helpful to include a question regarding attendees' motivation to seek help following the conference. Furthermore, without a control group who did not hear about OCD and its treatment, it is not possible to determine whether changes in attendees' confidence and belief ratings were the result of attending the conference or simply repeating the measures themselves. Additionally, the OCD-UK conference incorporates many different elements (including supportive environment, confronting stigma, attending lectures and workshops run by people with personal experience of OCD and professionals with expertise in the area of OCD). It is not possible to isolate what elements contributed to what changes in confidence and beliefs ratings pre and post conference. For these reasons future research with control and comparison groups is welcomed.

While the Therapy Relevant Beliefs Patient Scale (Stobie, 2009) had good test-retest reliability, it was adapted for the conference and requires further validation within this setting. For example, OCD-UK may consider removing the perceived poor past therapy subscale for future conferences as it is less relevant in this context. Nevertheless, OCD-UK plans to administer the pre- and post-questionnaire at their next annual conference as it had a high completion rate (91 of 149) and provided sufficient information for them to determine whether they had met their aim.

In summary, the present study supports OCD-UK's use of conferences to increase understanding of OCD and its treatment. This provides promising evidence for the use of such approaches in other third sector organisations and demonstrates the importance of using systematic evaluation procedures to evidence-base their effectiveness. Future research should evaluate the use of conferences for other physical and mental health conditions as a means promoting confidence and addressing unhelpful beliefs relating to treatment. Lastly, it illustrates the benefits of meaningful collaboration between people with personal experience, and healthcare and research professionals, to promote positive beliefs about OCD and its treatment that is grounded in research evidence and supported by people's lived experiences.

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Critical Review of Literature

Solution Focused Approaches in an Intellectual Disabilities Context: A Narrative Review

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Solution-Focused Approaches in an Intellectual Disabilities Context: A Narrative Review

Abstract

Purpose: Solution-Focused Brief Therapy (SFBT) has a growing evidence base for the general population. Several authors have recognised the advantages of applying this short-term, goal-focused and client-directed approach in intellectual disabilities (ID) and its evidence-base in this context is growing. However, it has not been critically evaluated. The purpose of this review is to summarise and critique the literature that has used solution-focused (SF) approaches in ID, and consider the implications for future research and clinical practice. **Methodology and findings:** A narrative literature review identified 12 studies that described or evaluated the application of solution-focused approaches; six used SFBT with individuals with IDs and six used Solution Focused Counselling (SFC) with staff and families. **Research implications:** The evidence-base primarily consists of case studies, and while they were generally of good quality, this limits the conclusions that can be drawn regarding the effectiveness of SF approaches in this context. There is a need for further controlled studies, with valid and reliable outcome measures, larger samples and longer follow-ups. **Practical implications:** Overall the reviewed studies offered preliminary evidence for the effectiveness of SFBT for individuals with mild ID and SFC for care staff working with individuals with moderate and severe ID, in particular in cases where clients' behaviour challenges. ID services should consider offering SF approaches on this basis. For individuals with ID, SF techniques should be modified to accommodate for their cognitive abilities and carers should be involved in sessions where possible. The 'miracle question' technique was consistently considered too abstract and unhelpful, regardless of whether it was used for individuals with ID or their family and carers. Hence, it should be re-phrased so that it is more concrete and focused on coping, strengths & competencies.

Keywords: *Intellectual disability, learning disability, solution-focused, solution-focused brief therapy, solution-focused coaching, solution-focused consultation*

Solution-Focused Approaches in an Intellectual Disabilities Context: A Narrative Review

Introduction

Psychological difficulties and people with intellectual disabilities

Estimates suggest that there are over 1.5 million people in the United Kingdom (UK) who meet the criteria for an Intellectual Disability (ID) (Emerson et al., 2012). ID is defined by the presence of significant impairments in intellectual functioning and adaptive functioning, with an age of onset before adulthood (British Psychological Society [BPS], 2000)[1]. People with IDs are at increased risk of adverse life events, and some have argued that this contributes to a greater vulnerability to psychological difficulties (Martorell et al., 2009; Vereenooghe & Langdon, 2013; Wigham, Taylor, & Hatton, 2014). They also have an increased genetic vulnerability to mental health problems (Vereenooghe & Langdon, 2013). Prevalence rates of mental health problems in this population range from 10 to 40.9% (Cooper et al., 2007a; Cooper, Smiley, Morrison, Williamson, & Allan, 2007b; Emerson et al., 2012; Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2001). Additionally, 10-15% of people with IDs are reported to have behaviour that challenges (e.g. aggression towards others, destruction, self-injury) (Cooper et al., 2009a; Cooper et al., 2009b; Emerson et al., 2012; Lowe et al., 2007). It is clear therefore that the treatment of mental health and behavioural difficulties in people with ID should represent a significant priority.

Historically, people with IDs were not offered psychological therapies that would routinely be offered to members of the general population with the same difficulties (Willner, 2005). Most commonly, interventions previously consisted of pharmacological medication or behavioural interventions delivered indirectly via staff. This has gradually changed, and recent meta-analyses have demonstrated

[1] Internationally there are variations in the terminology used for this population (i.e. "Intellectual Disability", "Learning Disability", "Mental Retardation" and "Developmental Disability"). While there is international consistency regarding the three criterion for ID, the wording of these varies (American Psychiatric Association [APA], 2013; Department of Health, 2001; BPS, 2000; World Health Organization [WHO], 1992). The ranges of ID in different classification systems do not correspond exactly but broadly they are as follows: borderline (IQ 70-79), mild (IQ 50-70), moderate (IQ 30-50), severe (IQ 50-35) and profound (IQ below 20) (BPS, 2000).

that people with ID, mostly within the mild range, can also benefit from individual psychological therapy (Nicoll, Beail, & Saxon, 2013; Prout & Nowak-Drabik, 2003; Vereenooghe & Langdon, 2013). This evidence base is strongest for Cognitive Behavioural Therapy (CBT) for anger and depression (Nicoll et al., 2013; Vereenooghe & Langdon, 2013). In these studies, the protocols that were originally developed for the general population were often modified to accommodate for the cognitive abilities of people with IDs, as per the guidance from the Royal College of Psychiatrists (RCP; 2004). The guidance also emphasises that therapists should be creative and flexible in tailoring techniques to individuals with IDs (RCP, 2004). Additionally, studies have highlighted the benefits of involving carers in sessions to aid communication and outside of sessions to reinforce lessons learned in therapy (Willner, 2005). Whilst protocol modifications such as these can benefit people with mild IDs, it is unclear whether protocols can be sufficiently adapted for people with more significant impairments in intellectual functioning (Campbell, Robertson, & Jahoda, 2014).

Several authors (Bhaumik, Gangadharan, Hiremath, & Russell, 2011; Hastings, 2013; Vereenooghe & Langdon, 2013; Willner, 2005) have highlighted that in comparison to the general population, there remains paucity in the evidence base for psychological therapies for people with IDs. Most of the evidence is based on expert opinion, descriptive single case studies, or uncontrolled and non-randomised studies with small sample sizes (Bhaumik et al., 2011; Hastings, 2013; Oliver et al., 2002; Vereenooghe & Langdon, 2013; Willner, 2005). Oliver et al. (2002) acknowledge that there are a number of obstacles to conducting Randomised Control Trials (RCTs) in ID: difficulties obtaining informed consent from individuals and when appropriate their carers; having a smaller client base to recruit from; offering Care As Usual (CAU) being sometimes perceived as inappropriate. For meta-analyses, there is the additional obstacle of comparing the outcomes of studies when samples differ in their ranges of IDs and studies frequently failed to report how ID ranges were measured (Vereenooghe & Langdon, 2013).

Campbell et al. (2014) highlighted that whilst RCTs help to establish efficacy, other (less robust) studies can provide information regarding "the translation of evidence-base to everyday clinical practice". Thus far, the research that has been published clearly evidences possible benefits of psychological approaches for people with IDs. Hence, further robust investigations should be prioritised so that ID research can catch up with that of the general population (Hastings, 2013).

Solution-Focused (SF) approaches

Over the last twenty years, Solution-Focused Brief Therapy (SFBT) has gained popularity as a psychological approach in the general population (Gingerich & Peterson, 2012). It is a short-term (generally six sessions), goal-focused and client-directed approach, originally developed by de Shazer and colleagues (1985; 1986; 2007). The central assumption of SFBT is that therapy should support a client to reach his or her goals by constructing solutions rather than analysing problems (Beyebach, 2000; De Shazer et al., 1986, 2007; Gingerich & Eisengart, 2000; Trepper et al., 2012). Other core assumptions include: there will be exceptions when the problem is absent or reduced; clients have the strengths and resources to change; and interactions between the clinician and client should be collaborative. SFBT draws from a range of techniques, which are outlined in Table 1 (Beyebach, 2000; De Shazer et al., 1986, 2007; Gingerich & Eisengart, 2000; Trepper et al., 2012).

Table 1

Description of SF techniques

Technique	Description
Problem Free Talk	Discussion about the client's life to facilitate exploration of his/her interests, resources and strengths.
Pre-Treatment Change	Exploration of helpful strategies used previously and of examples of prior coping.
Exception Seeking	Investigation of occasions when the problem was absent, reduced or manageable.

Scaling	The client is asked to rate his/her problem and goal on a 10-point scale, and to operationalise the different points on the scale. Questions are asked about how they reached their current point on scale, what is preventing moving down the scale, how they would know they were moving up the scale and what could help them to do this.
Goals	Identifying the client's personal goals and encouraging him/her to formulate goals that are detailed, specific, realistic and observable.
Hypothetical Future	Exploration of the client's description of a future when the problem is absent, reduced or manageable. There are a number of different wordings for the hypothetical future, but the best known is de Shazer's (1988) "Miracle Question". The client is asked, "suppose that one night when you were asleep, there was a miracle, and this problem was solved. The miracle occurs while you are sleeping, so you do not immediately know that it has happened. When you wake up what are the first things you will notice that will let you know there has been a miracle?"
Task	The client is encouraged to do inter-session tasks. These can be observing exceptions, doing more of what works or trying something different.
Compliments	The clinician makes observations of exceptions, strengths, resources and motivation shown by the client.
Competence Questions	The clinician asks questions to explore how the client effectively used his or her resources and strengths. Competence questions can also be considered indirect compliments as they helped the client to identify his or her resources and success.
Eliciting, Amplifying, Reinforcing and	The practitioner begins by eliciting, "what is better?" When the problem is better, the clinician amplifies, "what exactly is better"; then reinforces, "how did you manage to do that"

Start again	and then starts again, "what else is better". If the problem has not changed or has worsened, any disappointment is acknowledged. EARS can then be used to explore how the client kept things stable or how the client managed difficulty in the past. Reorientation to the goal might also be necessary.

SFBT has an emerging evidence-base in the general population, across a variety of settings: mental health care, social care, criminal delinquency, occupational rehabilitation and health management (Gingerich & Peterson, 2012; Kim, 2007). It has been used with adults, children, couples, families, groups and organisations (Corcoran & Pillai, 2009; Gingerich & Peterson, 2012; Kim, 2007; Stams, Dekovic, Buist, & de Vries, 2006). Meta-analyses have found SFBT to be an effective intervention for a range of problems in the general population; these include depression, anxiety, self-harm, suicidal ideation, alcohol abuse, obsessive-compulsive disorder, posttraumatic stress disorder, eating disorders, psychoses, carer stress and relationship conflict (Corcoran & Pillai, 2009; Gingerich & Peterson, 2012; Kim, 2007; Stams, Dekovic, Buist, & de Vries, 2006). A recent meta-analysis found that in 32 of 43 controlled outcome studies there had been a statistically significant benefit of SFBT and a further 10 indicated positive trends (Gingerich & Peterson, 2012). The strongest evidence was for adults with depression (Gingerich & Peterson, 2012). Another meta-analysis found that SFBT had larger effects when the problems were behavioural rather than interpersonal or mental health related (Stams et al., 2006).

SF approaches for people with ID

Several authors have recognised the possible benefits of SF approaches in the context of ID (Bliss, 2005; Roeden et al., 2009; Smith, 2005; Stoddart, McDonnell, Temple, & Mustata, 2001). Its focus on clients' strengths, competencies and empowerment is advantageous, as people with ID commonly will have the opposite experiences of deficiency and disempowerment (Roeden et al., 2009). Additionally, SFBT has been effectively used for a range of problems in the general population that people with ID also present with (Gingerich & Peterson,

2012). In particular, indications that behavioural problems respond well to SFBT is of interest to this population (Stams et al., 2006).

Whilst Roeden et al. (2009) suggested that SFBT techniques be adapted to meet the needs and cognitive abilities of people with borderline and mild IDs, this may be less appropriate for people with lower functioning, as they may not have the cognitive abilities to engage in these techniques. As an alternative, Roeden and colleagues (Roeden, Maaskant, Bannink, & Curfs, 2012; Roeden, Maaskant, & Curfs, 2014) suggest that a Solution-Focused (SF) approach with care staff is more appropriate for people with lower functioning. This is referred to as Solution Focused Coaching or Consultation (SFC) but essentially it incorporates the same techniques used in SFBT. The main difference is that for SFBT the focus is on the individual with ID's goals and competencies, whereas for SFC the focus is on the staff's goal for working with an individual with ID and the competencies staff have to achieve their goals (Roeden et al., 2012). Thus, another advantage of a SF approach in ID is that people with lower functioning can indirectly benefit through the work of their carers and family.

In summary, over the last twenty years, SFBT approaches have grown in popularity. Several authors have recognised the potential benefits of SF approaches in ID (Bliss, 2005; Roeden et al., 2009; Smith, 2005; Stoddart et al. 2001). However, to the author's knowledge, there is yet to be a review of the current evidence-base allowing for evaluation of the quality of the research thus far, synthesis of results and identifying gaps and areas requiring further research. A review would also be of practical value to commissioners, service managers and clinicians wishing to provide SF approaches in their services.

Aims

The aims of the current narrative review are to:

- Identify and summarise the literature that has applied SF approaches in the context of ID.
- Provide an overview of the research quality of the identified studies and consider the research implications.

- Outline how SF approaches were applied in the identified articles and discuss the clinical implications.

Method

Scope of review and search strategy

All research published from January 1990 to February 2016; on SF approaches in the context of ID was considered. The search terms are outlined in Table 2. For the purpose of this review an approach was considered SF if it used one or more of the techniques described in Table 1. Please note that specific learning difficulties (dyslexia, dyspraxia & dyscalculia) were not considered because they do not meet the criteria of global significant intellectual impairment required for an ID diagnosis (APA, 2013; WHO, 1992). The search strategy involved four stages: identification, screening, exclusion based on eligibility criteria and inclusion for analysis. *Figure 1*. depicts this process using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009).

Table 2

Search terms

Search term	Variation
Intellectually disability	"Intellectual* disab*" OR "learning disab*" OR "mental* disab*" OR "cognitive* disab*" OR "mental* retard*" OR "mental* handicap*" OR "mental* deficien*" OR "cognitive* deficien*" OR "intellectual* development* disorder*" OR "developmental* disab*" OR "developmental* difficult*" OR "intellectual* impair*" OR "cognitive* impair*" OR "idiocy"
Solution-Focused Approaches	"solution orientated" OR "solution focus*" OR "solution focus* therapy" OR "solution focus* counsel*" OR "solution focus* coach*" OR "solution focus* brief therapy" OR "solution focus* brief counsel*" OR "solution focus* brief coach*" OR "solution focus* family therapy" OR "brief intervention" OR "brief counsel*" OR "client directed" OR "person directed"

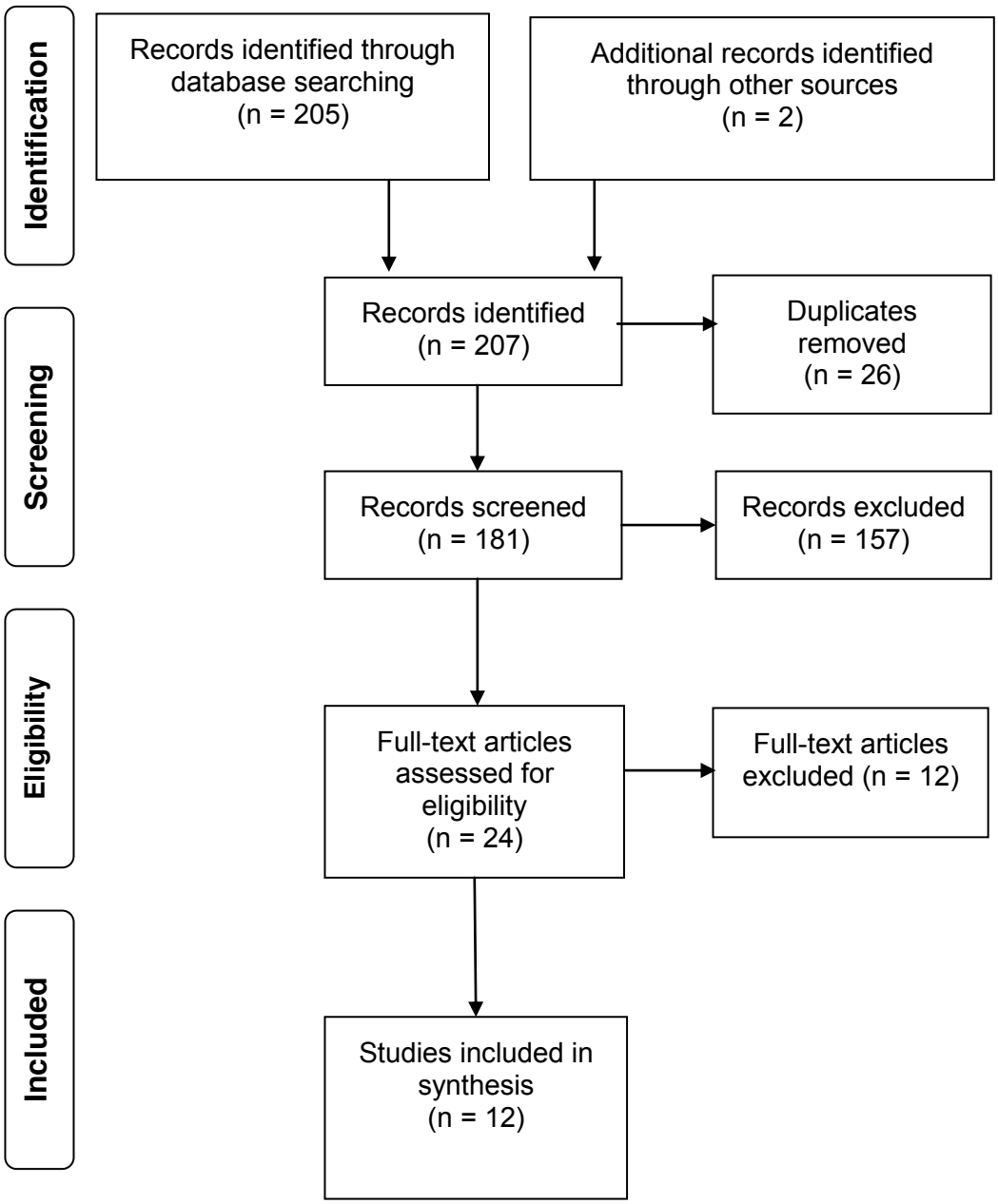

Figure 1. PRISMA flow diagram outlines the four stages of the search strategy

Identification. On 6th February 2016 the study search terms (Table 2) were entered into the PsychNET database, yielding 163 results, and Web of Science database, with 42 results. Three further articles were identified through manual searching of the reference lists of the articles identified and Google Scholar searches of other research that had cited the articles identified. In total, 26 duplicates were removed.

Screening. A total of 181 results were screened. The titles and abstracts were read. They were excluded if they did not consider the application of SF approaches to people with ID. Articles were also excluded at this stage if it was clear that the eligibility criteria were not met. Thus, 157 results were excluded.

Eligibility and inclusion. Full-texts were obtained for the remaining 24 articles. They were reviewed thoroughly to ensure they met the review's eligibility criteria, resulting in 12 being excluded (see Table 3). A final number of 12 articles were included in the review.

Table 3

Exclusion criteria and number excluded for these reasons

Reasons for exclusion	Number
• Participants did not have an ID or they were not the carer or family member of a person with an ID.	1
• Insufficient information was provided to determine the presence of an ID or the research was not conducted in a service for people with IDs, their carers and their family.	2
• The study did not include one or more of the techniques outlined in Table 1.	3
• The research was unpublished.	0
• The article was a review rather than an original research paper.	0
• The research was not a research article (e.g. book, book chapter, thesis, dissertation, conference abstract and guidelines)	2
• The study investigated questionnaire validity or methods of	1

evaluating SF	
• The study was not published in English.	3

Data Abstraction and analysis

Data was abstracted from each of the identified articles, using an abstraction form (Appendix L), which was then summarised. Separate tables are used for SFBT for individuals with ID and SFC for staff and families. (Please note in Lloyd & Dallos's 2006 & 2008 studies, they described SFBT for families but as this predominantly did not involve direct work with individuals with IDs it has been included under SFC). The tables are grouped by information relating to study design and participants (Tables 4 and 5 for SFBT and SFC respectively) and delivery of SF approaches (Tables 6 and 7, SFBT and SFC respectively). A synthesis and critical appraisal of the research quality is provided in the text. To aid this process, the Centre for Evidence-Based Management's (CEBM) checklist for critical appraisal of cases studies was used (Appendix M). It was considered the most appropriate appraisal tool, as the majority of the literature in this area adopted a case study design. Based on this appraisal tool, study quality was categorised as follows: poor, acceptable, good and very good.

Findings and Discussion

Studies' design and participant details

***Design*.** The most commonly used design was single cases (n=4; Bliss, 2005; Murphy & Davis, 2005; Rhodes, 2000; Smith, 2005), followed by qualitative studies (n=3; Lloyd & Dallos, 2006, 2008; Smith, 2011), case series (n=2; Roeden, Maaskant, Bannink, & Curfs, 2011; Roeden et al., 2012), controlled studies (n=2; Roeden, Maaskant, & Curfs, 2014a; Roeden et al., 2014b) and lastly a descriptive service evaluation (n=1; Stoddart et al., 2001). Most were considered to be 'good' quality based on the CEBM's checklist for critical appraisal of case studies but they were predominantly descriptive rather than evaluative. Nevertheless, the quality and richness of the descriptions of SFBT (Table 4) and SFC (Table 5) in these studies were welcomed given that SF approaches in the context of ID are a newly developing area. Despite this, the conclusions that can be drawn about the effectiveness of such approaches are limited by the reliance on case study

methodologies, with a lack of robust measures, baseline and follow-up measurement, control groups and randomisation (Bhaumik et al., 2011; Hastings, 2013; Vereenooghe & Langdon, 2013; Willner, 2005). The recent studies conducted by Roeden and colleagues (2014a; 2014b) have started to address these issues in studies examining SFBT for individuals with mild ID and SFC with care staff working with people with moderate and severe ID.

Nevertheless, there remains room for improvement. Roeden et al. (2011, 2012, 2014a; 2014b) emphasised the need for longer follow-up periods, larger samples, control samples and full randomisation (i.e. RCTs). Furthermore, replication of the research conducted by Roeden and colleagues is warranted to ensure their findings are valid and reliable. Additionally, it is possible that the successful outcomes reported in their studies could be attributed to non-specific therapy factors (the client-therapist relationship) rather than specific factors (SF approach and techniques). Hence, SF approaches should be compared to other active treatments to determine their efficacy.

Sample size. Sample sizes were relatively low as would be expected given that most of the studies used a single case study design (see Tables 4 and 5 for details of SFBT and SFC participants, respectively). Sample sizes remained low for the two controlled studies completed by Roeden et al (2014a; 2014b), who appropriately noted that this might have meant that there was insufficient power to detect statistically significant differences between the groups in their studies. Additionally, small sample sizes limit generalisability. Nevertheless, Oliver et al. (2002) acknowledged that in ID service settings there is a restricted client base to recruit from and this is a plausible reason for small research sample numbers when compared with similar research conducted by mainstream services.

Outcome measures. Studies used a range of different measurement tools. The SF technique of scaling was widely used and could also be considered an idiosyncratic self-report measure. Scaling appeared to be a meaningful measure for participants (e.g. Rhodes, 2000). However, pre-post differences in scaling scores were rarely reported and when they were reported it was not in a results

section, making it difficult for the reader to identify the information. Positive qualitative feedback and descriptive outcomes were consistently reported in studies using single case designs. These forms of measurement are client-centred, but do not necessarily promote validity.

Standardised measures (see Table 4 and 5) were also used for evaluating satisfaction with the intervention, therapeutic relationship, quality of life, psychological problems, goal attainment, pro-active thinking and resilience. Use of such measures can positively impact validity. As mentioned previously, in SF approaches clients (whether they are individuals or groups) identify their goals for therapy. Roeden et al. (2014a, 2014b) recognised standardised measures may not correspond with these goals. Nevertheless, this does not apply to the Scale Question Progression ([SQP]; Bannink, 2010), which is based on individuals' goals. In sum, there are strengths and limitations of the different forms of measurement. Hence, simultaneous use of several various forms of measurement is suggested.

Table 4

Information relating to the design and participants of studies using SFBT for individuals with ID

Article	Setting and Recruitment	Design and Samples[b]	Data collection[c]	Key findings[d]	Study quality
1. Stoddart et al. (2001)	Setting: Community ID services Country: Canada ID screen: DSM-IV Recruit: CR & SR Referral reasons: Social difficulties (n=8), Couples conflict (n=6), Anger/aggression (n=5), Depression/anxiety (n=4), Bereavement (n=3), Sexual issues (n=2), Occupational problems (n=2), Low self-esteem (n=1), Family difficulties (n=1), Independence issues (n=1)	Design: service evaluation, comparing two therapies Intervention group: SFBT Number of session: 8 Sample size: n=16 Drop out: n=13 (not included in analyses) Age: min 23 Gender: 6 Male: 10 Female ID: Borderline ID (n=4), Mild ID (n=12) Comparison group: long-term therapy Other sample details not reported	Retrospective review of client records Client satisfaction: Mean scores on SEQ at 6-month post Therapy success: Average clinician 5-point Likert scale ratings for the therapy success, at post.	Post SFBT average clinician ratings of therapy success were higher for those with higher functioning, fewer presenting problems, who had support from carers in and between sessions and who had self-referred. 6 months-post clients & carers report higher satisfaction in the SFBT group (mean= 26.35) than the comparison group (mean=24.89) SFBT was delivered in shorter length of time (mean 118 days) than comparison (mean 372 days)*	Good
2.Bliss (2005)	Setting: Community ID service Country: UK ID screen: SC	Design: Case study Intervention: SFBT Number of sessions: 11 with client and 1 session with staff only	Care staff and therapist observations & comments	Reported observations of positive benefits of SFBT for the client from support staff (e.g. tidying room, requesting to come to	Acceptable

	Recruit: CR Referral reasons: Challenging behaviour (n=1)	Sample size: n=1 Age: 45 Gender: Female ID: Mild/Moderate ID		therapy and reductions in challenging behaviour). Reported therapist observations (e.g. reduced anxiety attending sessions & requests to re-arrange cancelled appointments).	
3. Smith (2005)	Setting: Community ID service Country: UK ID screen: SC Recruit: SR Referral reasons: Aggression (n=1)	Design: Case study Intervention: SFBT Number of sessions: 5 Sample size: n=1 Age: 45 Gender: Male ID: Mild ID	Client self-reported incidence of aggressive behaviour at pre, during and 9-month follow-up	Pre SFBT the client had been involved in three physical fights (within 6-month period), from first SFBT session and at 9-months post there had been no incidents of physical aggression.	Acceptable
4. Murphy & Davis (2005)	Setting: Residential school for students with significant IDs Country: US ID screen: SC Recruit: CR Referral reasons: Challenging behaviour	Design: Case study Intervention: Self-modelling & exception seeking Number of sessions: 5 Sample size: n=1 Age: 9 Gender: Male ID: Moderate ID	Momentary time sampling (10-second intervals) measuring client use of expressive signs during randomly selected 10 minute classroom recording. Mean percentage calculated.	Expressive signing increased from start (23.23%) to end (71.43%) of therapy and was maintained at one-month follow-up (64.17%). Informal positive feedback from client & teacher obtained.	Very good

	('unacceptable' ways of expressing needs e.g. pointing, hitting, yelling) (n=1)				
5. Roeden et al. (2011)	Setting: Day and residential service provider for adults with IDs Country: Netherlands ID screen: WISC-III-NL for adults, WAIS-III-NL for children & SRZ Recruit: CR Referral reasons: Alcohol (n=3), Anger (n=2), Bereavement (n=1), Depression (n=1), Sleep difficulties (n=1), Low self-esteem (n=1) Anxiety (n=1)	Design: Case series Intervention: SFBT (n=10) Number of sessions: 7 Sample size: n=10 Age: Mean 39 Gender: 3 Male: 7 Female ID: Mild ID (n=10)	Quality of life: Client completed IDQOL, at pre, post and 6-week follow-up. Maladaptive behaviour: Staff completed RSMB, at pre, post and 6-week follow-up. Client reports of goal attainment: SQP, at pre, post and 6-week follow-up. Staff reports of clients' goal attainment: GAS, at pre, post and 6-week follow-up. Client satisfaction with treatment and therapeutic relationship: adapted SRS, completed at every session.	Pre to post clients' psychological functioning improved (7/10 clients)* and was maintained at 6-week follow-up (6/10 clients)*. Pre to post clients' social functioning improved (2/10 clients) and further improvements were seen at 6-week follow-up (4/10 clients). Pre to post there were clinically relevant decreases in maladaptive behaviour (8/10 clients) and these were maintained at 6-week follow-up. There were progressions in goal attainment reported by (7/10) clients* and (7/10) staff*and these were maintained at 6-week follow-up for both clients* and	Very good

				carers*. Clients assessed treatment and therapeutic relationship positively.	
6. Roeden et al. (2014a)	Service and recruitment details are the same as Roeden et al. (2011) Referral reasons: Alcohol (n=3), Anger (n=2), Bereavement (n=2), Depression (n=2), Sleep difficulties (n=1), Low self-esteem (n=3), Anxiety (n=1), Couples conflict (n=2), Self-help (n=2), Social phobia/ relationship difficulties (n=2)	Design: Controlled study Intervention group: SFBT Number of sessions: 6 Sample size: n=20 Drop out: n=2 Age: Mean 43.4 (range 18-60) Gender: not stated ID: Mild ID (n=20) Comparison group: CAU Sample size: n=18 Age: Mean 41.5 (SD = 4.9) Gender: not stated ID: Mild ID (n=18)	Client (SFBT group only) report of goal attainment: SQP, at pre, post and 6-week follow-up. Quality of life: Client completed IDQOL, at pre, post and 6-week follow-up. Maladaptive behaviour: Staff completed RSMB, at pre, post and 6-week follow-up. Resilience: Client completed POS, at pre, post and 6-week follow-up.	2/10 clients terminated SFBT prematurely. Pre to post, SFBT group showed clinically relevant progression toward treatment goals (13/18) * and at follow-up (14/18)*. Pre to post, SFBT group outperformed the CAU group on psychological functioning*, social functioning*, maladaptive behaviour*, autonomy* and social optimism*. At 6-week follow-up these were maintained for psychological functioning*, social functioning* & maladaptive behaviour*.	Very good

Notes.
[a] SC = service criteria, CR = clinician referral, SR = self-referral, WISC-III-NL = Wechsler Intelligence Scale for Adults-III (Wechsler, 2005a), WAIS-III-NL = WAIS-III-NL, Wechsler Intelligence Scale for Children- III (Wechsler, 2005b), SRZ = Dutch adaptive behaviour scale (Kraijer & Kema, 1994)

[b] CAU = Care As Usual
[c] SEQ = Service Evaluation Questionnaire (Nguyen, Attkisson, & Stegner, 1983), IDQOL = Intellectual Disability Quality of Life, including the psychological & social functioning subscales (Hoekman, Douma, Kersten, Schurman, & Koopman, 2001), RSMB = Reiss Screen for Maladaptive Behaviour (Reiss, Minnen, & Van Hoogduin, 1994), SQP = Scaling Question Progression (Bannink, 2010), GAS = Goal Attainment Scaling (Schlosser, 2004), SRS = Session Rating Scale (Miller, Hubble, & Duncan, 1996), POS = Positive Outcome Scale, includes items relating to autonomy and social optimism (Appelo, 2005).
[d] Statistically significant = *

Table 5

Information relating to the design and of studies using SFC

Article	Setting & Recruitment[a]	Design & Samples[b]	Data collection[c]	Key findings[d]	Study quality
7. Rhodes (2000)	Setting: Residential care service for Severe ID Country: UK ID screen: SC Recruit: CR Referral reasons: Challenging Behaviour (food regurgitation) (n=1)	Design: Case study Intervention: SFC (n=1) Number of sessions: 4 ID client sample Size: n=1 Age: 36 Gender: 1 Female ID: Severe ID (n = 1) Staff sample: Two key workers. No further details reported.	Average daily frequency of challenging behaviour at pre and post.	Reduction in challenging behaviour pre (1.34) and post (0).	Acceptable
8. Lloyd & Dallos (2006)	Setting: Community ID service Country: UK ID screen: SC Recruit: RI to families on waitlist for psychology input. Referral reasons: Oppositional	Design: Qualitative case study Intervention: SFBT with families Number of sessions: 1 Family sample: Sample size: Families (n=7) Parent attendance: 1 Father and 7	Audio recording of initial sessions with seven families Analysed using thematic analysis	SFBT highlighted parents' competencies, goals and achievements. Process emerged relating to empowerment and integration of mothers' goals into their life narrative. The 'miracle question' prompted a shift from wishful thinking to problem solving. SFBT facilitated useful parent-professional partnership.	Very good

	problems(n=3), Depression/anxiety (n=3), Regurgitation & bowel management (n=1), Sexual issues (n=1), Anger/aggression (n=1), Sleep difficulties (n=1)	mothers Child age: Mean 8 (range 4-14) Child gender: 6 Male: 1 Female Child ID: Moderate ID (n=1), Severe ID (n=4), Profound ID (n=2) Family structure: two parents (n=3), one parent (n=1), blended (n=2) Mean number siblings: 1.4 (range 1-4)			
9. Lloyd & Dallos (2008)	Details are the same as Lloyd & Dallos (2006)	Design: Qualitative interviews Intervention: SFBT with families (n=7) Number of sessions: 1 Child & family demographics same as Lloyd & Dallos (2006) Interview sample Sample size: Mothers (n=7) Mother age: mean 41 (range 31-54)	Interviews with seven mothers following SFBT for families. Interview schedule guided by the HAT Analysed using Interpretive Phenomenological Analysis.	Themes identified regarding SFBT: it led to an idea of 'making the best of it', prompted examination of wishful thinking & fostered self-efficacy and supported the therapeutic relationship. The miracle question was perceived as the most “unhelpful” aspect of therapy.	Very good

		Mothers' employment: FT mother (n=2), FT professional (n=1), PT professional (n=2), PT Skilled/manual (n=2)			
10. Smith (2011)	Setting: Community ID social service Country: UK ID screen: SC Recruit: RI to 12 staff who attended a training workshop. All consented to participate but six could not for practical reasons. Referral reasons: n/a	Design: Qualitative interviews Intervention: 2-day SFBT workshop Staff sample Size: n=6 Drop-out= 12 consented to participate but for practical reasons only 6 could attend. Gender: 2 Male: 4 Female Training: Social work qualification (n=2), Social work assistant (n=4)	Interviews with social worker staff, 9-months post SFBT workshop. Interview schedule guided by the HAT Analysed using Thematic analysis.	Social workers reported that post-workshop their interaction (communication, collaboration, feelings of control and self-efficacy) with clients improved They reported that they had difficulty implementing the specific SF techniques. This was linked to limited opportunities for practice, limited peer and organisational support and perceived conflicts between SFBT and professional role.	Very good
11. Roeden et al. (2012)	Setting: Residential and vocational service provider for children and adults with Moderate & Severe ID	Design: Case series Intervention: SFC Number of sessions: 3 Staff sample	Staff reports of team goal attainment: SQP, at pre, post and 6-week follow-up. Proactive thinking: SCIBI-PAT, at pre,	Post SFC, there were progressions toward team goals (7/13)*, improved proactive thinking (5/10)* and improved staff-client relationships (7/13)*. These were all maintained at 6-week follow-up*.	Very good

	Country: Netherlands ID screen: SC Recruit: SR from staff who experienced a support problem with a client. Referral reasons: Violent client behaviour, Imbalanced relationships, Communication problems, Lack of progress with clients	Number of teams: 13 Staff sample size: n=42 Age: mean 40.4 (SD = 11.1) Gender: 0 Male: 42 Female Teams: 12 (with 2-4 staff per team) Mean years employed in ID: 12.7 (range: 1-33; SD = 8.6) Training: 95% professional training (nursing, social work, occupational training), 5% high school degree	post and 6-week follow-up. Quality of therapeutic relationship between care staff and clients: STRS, at pre, post and 6-week follow-up. Satisfaction with procedure and collaboration: SRS, at every session.	Staff mostly assessed procedures and collaboration positively, except for one incident of lower scores (i.e. score below 9 out of 0-10) relating to the procedure for handling aggression and needing a longer duration of SFC to address some problems.	
12. Roeden et al. (2014b)	Details are the same as Roeden et al 2012	Design: Controlled study Total staff sample: Size: n=118 Teams: 44 (with approx.2-3 staff per team) Gender: 91% female Staff intervention group: SFC Number of sessions: not stated.	Staff reports of team goal attainment: SQP, at pre, post and follow-up (i.e. 15-weeks after commencement) Proactive thinking: SCIBI-PAT, at pre, post and follow-up (i.e. 15-weeks after commencement) Quality of therapeutic relationship between care staff	Post SFC, there were progressions toward team goals (10/18)*, which was maintained at 15-week follow-up*. Pre to post, SFC group outperformed the CAU group on pro-active thinking*, and quality of therapeutic relationships*. At follow-up these were maintained*.	Very good

	Size: n=59 Age: Mean 40.2 (SD = 10.8) Mean years of work experience: 12.5 (SD = 8.6) Staff comparison group: Care As Usual Size: n=59 Age: Mean 39.1 (SD = 10.8) Mean years of work experience: 11.7 (SD = 5.8)	and clients: SRS, at pre, post and follow-up (i.e. 15-weeks after commencement)

Notes.
[a] SC = Service Criteria, CR = Clinician Referral, SR = Self-Referral, RI = Researcher Invitation
[b] CAU = Care As Usual, FT = Full time, PT = Part Time
[c] HAT = Helpful Aspects of Therapy Questionnaire (Llewelyn, 1988), SQP = Scaling Question Progression (Bannink, 2010), SCIBI-PAT = Staff-Client Interactive Behaviour Inventory subscale for proactive thinking (Willems, Embregts, Stams, & Moonen, 2010), STRS = Student Teacher Relationship Scale (Koomen, Verschueren, & Pianta, 2007), SRS = Session Rating Scale (Miller et al., 1996).
[d] Statistically significant = *

Setting. Information regarding the service setting and participant samples, along with referral reasons for SFBT and SFC is provided in Table 4 and 5, respectively. Of the 12 studies identified, six were from the United Kingdom (UK), four from the Netherlands, and one each from Canada and the United States (US). (Please note Lloyd & Dallos' studies (2006, 2008) used the same set of families and hence setting and participant details are only reported once). Studies were completed in community ID teams, offering psychological (n= 4) and social services (n= 1) on an outpatient basis. The remaining studies were conducted in residential and day care settings (n=5) and in a residential school (n=1), where psychological support was provided. All of the studies were conducted in routine practice settings (rather than research settings) and for that reason are likely to be representative of services generally. However, many ID services are multidisciplinary and clients in these studies were likely to have received other input, in addition to SF approaches (McParland, 2015). Although this does not necessarily invalidate any positive outcomes reported, it should be considered a limitation to internal validity. There was one exception; Stoddart et al. (2001) stated that participants did not receive any other input.

ID ranges and referral reasons. The majority of SFBT studies reported the ID ranges of clients but most did not outline the assessment procedures used to determine this. The ID ranges were as follows: four were in the borderline range; 43 in the mild range; one in the mild/moderate range; and one in the moderate range (Table 4). Stoddart et al. (2001) provided some clarification, stating that ID diagnosis based on Diagnostic and Statistical Manual of Mental Disorders (4th Edition) was a criterion for accessing the service. In addition, Roeden et al. (2011, 2014a) reported the instruments used to determine ID diagnosis (see Table 4). The remainder implied that clients met the criteria for ID diagnosis. The BPS (2015) acknowledges that it is not uncommon for ID services to make decisions regarding ID ranges based on clients' histories and their and their carers'/families' reports of functioning. However, it strongly recommends that standardised instruments also be administered to assess IQ and adaptive functioning. Unfortunately, the general lack of information regarding ID diagnoses in the identified studies impacts external validity. People with ID have different levels of functioning and it is important to

provide ID ranges, as an indicator of the level of functioning required to engage with SF techniques and to benefit from them.

Currently, Roden et al. (2011, 2014) offer the most standardised screening procedures. They also used valid and reliable measures at pre, post and follow-up and found that SFBT was effective in addressing a range of problems (see Table 4) for people with mild IDs. In addition, Stoddart et al. (2001) found participants with IDs who self-referred, who had fewer presenting problems and whose problems were around poor self-esteem, family relationships and bereavement performed better on clinician ratings of success post-SFBT. Those with depression, anxiety, couples conflict and independence issues were the least successful but in other studies SFBT was considered helpful in addressing these problems (Table 4). It is positive that SFBT has been applied to a range of problems, but, unfortunately, on the basis of these studies alone it is not possible to draw firm conclusions about which problems are best addressed using SFBT. Moreover, none of the identified studies offered SFBT to individuals requiring psychological input for severe mental health problems (e.g. schizophrenia, bi-polar disorder), risk to self and others, and abuse or trauma work.

Even less information was reported in SFC studies regarding ID diagnosis, with most stating the general ID ranges (moderate, severe and profound) of the clients staff were working with (Table 5) but not the screening procedures used. Care staff self-referred to SFC if they had support related problems and families were either clinician- or self-referred for a variety of reasons (Table 5). The most common referral reason was related to challenging behaviour, with studies consistently reporting that SFC was helpful in addressing these issues. This included studies by Roeden et al. (2012, 2014b), which were considered to have reasonably robust methodologies.

Drop-out rates. In SFBT, dropout was generally low (Table 4), implying that the intervention is well received and accepted by clients. However, in Stoddart et al.'s (2001) study 29 clients were initially referred to SFBT. Of these, 13 did not complete therapy: five withdrew their request for therapy, five were re-directed to

long-term therapy, two dropped out after one to two sessions and one had not yet completed therapy. Two of those who did not complete therapy had moderate ID and were the only clients with this level of functioning that had been referred to SFBT in this study. An additional two dropped out of Roeden et al.'s (2014a) study for the following reasons: lack of trust in the treatment; dissatisfaction with the therapeutic relationship; pressures from family or others to withdraw; and treatment was not a personal choice. Furthermore, in one of the SFC studies, a child with ID and autism attended the family session (Dallos & Lloyds, 2006). They report that SF concepts were problematic for him due to poor understanding of the future, difficulties differentiating between fantasy and realities and difficulties focusing on the whole rather than details. These examples raise questions regarding the appropriateness of directly using SF approaches for some individuals with ID.

Demographics. In terms of demographical information, gender was reported in the SFBT studies. Both males (n=11) and females (n=18) with IDs were represented (Table 4). It appears that females with IDs are more likely to be offered individual SFBT, than men. Unfortunately, of the studies with the most robust methodologies, two did not investigate the impact of gender on outcomes (Stoddart et al., 2001; Roeden et al. 2011) and one did not report gender breakdowns (Roeden et al., 2014). It was a strength that people with IDs across the lifespan (9-60 years old) were included (Table 4), as it suggests it is applicable for people with IDs of varied developmental ages and life stages, who are likely to present with different needs and problems. Hence, reviews of SFBT for the general population have tended to consider its application across the lifespan (e.g. Kim, 2009). However, only Murphy & Davis (2005) used SFBT with a child (9 years old). While this case study had a reasonably strong design (reliable measurements at pre, post and follow-up), further studies would be required to determine the effectiveness of SFBT with children with IDs. In the remaining studies, the mean age range of participants with IDs fell between 39 and 45. In SFC studies, the gender and ages of the clients with IDs that care staff were working with were rarely reported. Care staff and families receiving SF approaches were predominantly female. Across the studies, reporting of ethnicity and socio-

economic status was variable, which unfortunately reduced generalisability and consideration of these factors within the context of the intervention.

Delivery of SF approaches

The identified studies differed in how SF approaches were delivered. All of those in the borderline and mild ranges received individual SFBT (Table 6). Whilst no individual with severe or profound ID was offered SFBT, one adult with mild/moderate ID received SFBT (Bliss, 2005). Additionally, one child with moderate ID received an individual intervention that was based on self-modelling and the SF technique, exception-seeking (Murphy & Davis, 2005). Session numbers for SFBT with people with ID ranged from five to eleven. While a chief characteristic of SFBT is that it is "brief" (normally six sessions), some studies (Bliss, 2005; Roeden et al., 2011; Stoddart et al., 2001) suggested that individuals with ID benefit from additional sessions. Similar recommendations for other psychological approaches for people with ID have been made in the literature (Campbell et al., 2014).

When SFC was provided it was always for care staff working with clients with moderate, severe and profound ID (Table 7). Care staff received between three and four sessions. Rhodes (2000) suggested that SFC was a good starting point that could then be integrated with other approaches. It is not clear whether SFC alone is a sufficient intervention for care staff experiencing difficulties providing support or whether additional approaches (e.g. behavioural) will be required. For the families in Lloyd & Dallos' (2006, 2008) studies, only their initial session was reported. The authors state that some families went on to have further SF input or other input; the details of what this entailed were not reported. Although it is uncertain whether SFC alone is sufficient, the findings of Roeden et al. (2014b) indicate that it is superior to CAU, at post-treatment and at follow-up. An additional study, by Smith (2011) provided a two-day workshop on use of SF approaches for social work staff working with individuals with ID. Unlike the other studies using SFC, this meant there was not a focus on a particular client. This perhaps contributed to the social work staff reporting difficulty implementing the techniques taught in the workshop. In comparison, care staff and families from the other

studies assessed the SF approach and techniques more favourably (e.g. Rhodes, 2000; Roeden et al., 2012; 2014b).

The clarity of description and use of examples regarding the SF techniques and adaptations in all the studies identified was welcomed, particularly for clinicians hoping to develop their understanding of how to use SF approaches in their practice. The level of experience and training SF practitioners had in these studies varied; some had informal experience and some had formal training. Almost all studies actively sought to encompass the core assumptions and techniques of SF, suggesting these were attempts to ensure treatment fidelity, although no formal evaluation of this was reported.

SF techniques. Of those studies using SFBT for individuals with ID, a range of SF techniques were utilised (Table 6). The average number of techniques used per study was six (range two-ten). Few of these studies used specific SFBT treatment protocols. The exceptions were Roeden et al. (2012, 2014a), who had the most robust methodologies and stated that they used a consistent format for each session that primarily adhered to the standard SFBT protocol developed by De Shazer et al. (2007). However, Smith (2005) found that using fewer techniques was less “confusing” for clients with IDs. In addition, Murphy & Davis (2005) exclusively used video feedback as means of exploring exceptions and self-modelling desired behaviour. This stands out as a resourceful method to engage a client with moderate ID and limited expressive language. The most commonly used techniques were: scaling (n=5); exception seeking (n= 5); compliments (n=4); competency questions (n=4); and hypothetical future (n=4). There is a degree of overlap between the different techniques and for this reason it is possible that some studies used other techniques but did not explicitly stated this. In comparison, in SFC a larger number of techniques were used (average: 8.6 and range: 7-10; Table 7), which is consistent with standard SFBT protocol developed for the general population (De Shazer et al., 2007).

Adaptations to individual SF therapy. As would be expected, additional adaptations were made for individuals with ID that were not used for care staff and

families in SFC; for the most part these were consistent with regular recommendations for adapting psychological therapies for people with IDs (RCP, 2004).

Firstly, clients with ID were supported by a carer or family member during and in-between sessions (Bliss, 2005; Roeden et al., 2011, 2014a; Smith, 2005; Stoddart et al., 2001). It was found that carers and family members could remind clients about inter-session tasks and help them in their completion. Carers also helped clients to understand and respond to the questions asked by the SF therapists. Stoddart et al. (2001) found that clients who were supported by carers in and between sessions had significantly better outcomes (clinician ratings of therapy success) than those who weren't supported by carers.

Secondly, scales were adapted: using shorter scales (2- or 3-points); using pictorial scales; having scales on a vertical axis rather than horizontal axis; using concrete examples (thermometer); and basing scales on specific behaviours (Bliss, 2005; Stoddart et al., 2001).

Thirdly, adaptations to exception seeking were suggested. These included using role-play, videotalk and actual videos to make exception seeking more concrete for clients (e.g. Murphy & Davis, 2005; Smith, 2005). Fourthly, the importance of helping clients to structure responses to competency questions was emphasised. Bliss (2005) described how when a client was asked, "How did you do that?", she would respond, "I don't know". The client was given additional structure to help her answer. They found that when she was given options, she was able to pick the response that fitted for her.

Lastly, the most common technique requiring adaptation was the "miracle question", regardless of whether it was for clients with IDs, their family or their carers. For example, in Stoddart et al.'s study (2001) individuals with ID clients were asked "what their wish for therapy was, what their wishes for their life were, or how they would know therapy was finished" and in Roeden et al. (2014a; 2014b), they asked carers to consider "when you look forward and things have improved,

what will you be doing differently?" Interestingly, there was an exception to this, Lloyd & Dallos (2006) observed that in sessions with mothers of children with IDs, the 'miracle question' prompted a shift from wishful thinking to problem-solving. However, in a follow-up study the mothers reported that the 'miracle question' was the least helpful aspect of therapy (Lloyd & Dallos, 2008). Hence, Lloyd & Dallos subsequently recommended that the question be re-worded.

Table 6

Information relating to the delivery of SF approaches of studies using SFBT for individuals with ID

Article	Modality & sessions[a]	Technique	Adaptations	Therapist experience
1. Stoddart et al. (2001)	8 SFBT sessions with borderline & mild ID	S, G, T, HF	S- horizontal visual 3-point scales used to operationalise behaviour & measure happiness/sadness. HF- clients asked "what their wish for therapy was, what their wishes for their life were, or how they would know therapy was finished" T- the word homework not used. Instead termed "exercise or practice". Format- there was a lead therapist with reflecting team behind a one-way mirror. The lead therapist consulted with the reflecting team at least once per session. Support: family/carer support on inter-session task completion.	Several years of informal experience using SF
2.Bliss (2005)	11 SFBT sessions with client with mild/moderate ID.	PTC, ES, S, C, CQ	ES- additional structuring if client unable to answer "how did you do that?" she was given options. S- used visual 2-point scale. C & CQ- client found it difficult to engage with concept of HF. Instead focus was placed on her current strengths & coping. Support- carer support on inter-session task completion & 2 sessions with staff to explore PTC, S & ES.	4 years experience using SF
3. Smith (2005)	5 SFBT sessions with client with mild ID.	PFT, S, ES, HF, C	Decision- focus on a few techniques as the client found it "confusing" to have too many techniques. ES- Using role-play helped to elicit coping & strengths. Support- carer support on inter-session task completion.	Informal experience using SF
4. Murphy & Davis (2005)	5 SF sessions (delivered over 5 days) with client with moderate ID.	ES, CQ	Integrated ES with self-modelling. Video footage of client using desired behaviour (communicative signing) was used to promote self-modelling and to amplify exceptions. Follow-up questions e.g. 'how did you do that?, what was different that time?". Idea of client	Psychology trainee. No other details stated.

			being a movie star who was being interviewed about the movie was used to introduce the technique.	
5. Roeden et al. (2011)	7 SFBT sessions with clients with mild ID.	PFT, PTC, G, HF, ES, S, C, CQ, T, EARS	HF-Used “miracle question” or alternatives e.g. “when you look forward and things have improved, what will you be doing differently?” Support: carers attended every session and provided support on inter-session task completion.	Not stated
6. Roeden et al. (2014a)	6 SFBT sessions with clients with mild ID.	PFT, PTC, G, HF, ES, S, C, CQ, T, EARS	Same as study 5. Roeden et al. 2011	Not stated

Notes.

[a] PFT = problem free talk, PTC = pre-treatment change, G = goals, HF = hypothetical future, ES = exception seeking, S = scaling, C = compliments, CQ = competence questions, T = tasks, EARS= eliciting, amplifying, reinforcing and starting again

Table 7

Information relating to the delivery of SF approaches of studies using SFC

Article	Modality & sessions[a]	Technique	Adaptations	Therapist experience
7. Rhodes (2000)	4 SFC sessions for care staff working with people with severe ID	G, PTC, ES, T, HF, C, CQ	ES- developed a list of "Helpful Guidelines" for staff outlining actions, which are linked to a reduction in the problem. HF-"what arrangements would be ideal for [client]?"	Not stated.
8. Lloyd & Dallos (2006)	1 SFBT session for families with children with moderate & severe ID.	PFT, PTC, ES, HF, S, G, C, T	HF- The "miracle question" was used but authors found that alternatives yielded fuller replies e.g. ''if I drove past in 3 months and saw things going really well, what would I see", "if therapy is successful what would you see?"	Training & supervision in SFBT.
9. Lloyd & Dallos (2008)	Same as Lloyd & Dallos (2006)	PFT, PTC, ES, HF, S, G, C, T	HF- mothers reported finding the 'miracle question' irrelevant and authors suggested using a different phrasing would be more helpful e.g. "what would a really good day look like?"	Training & supervision in SFBT
10. Smith (2011)	2-day SFBT workshop for social workers working with people with ID. 2 optional facilitated discussion offered several months post workshop.	Specific techniques delivered not reported.	Social workers reported that following the workshop their interaction (communication, collaboration, feelings of control and self-efficacy) with clients improved post workshop but they had difficulty implementing the specific SF techniques.	Social workers in ID service but no previous experience of SF. Trainer was a clinical psychologist.
11. Roeden et al. (2012)	3 SFC sessions for care staff working with clients with moderate & severe ID.	PFT, PTC, G, HF, ES, S, CQ, C, T, EARS	G-Before setting goal obtained a description on the problem. "What is the support problem with this person?" and "what is the problem for staff members?" HF-Used "miracle question" or alternatives e.g. "when you look forward and things have improved, what will you be doing differently?" and "suppose we make a video showing the most desirable support situation. What do you see and hear on this video?"	2 SF practitioners had master's degree in counselling & training on SF.

12. Roeden et al. (2014b)	SFC with staff, working with clients with moderate & severe ID. Session numbers not stated.	PFT, PTC, G, HF, ES, S, C, CQ, T, EARS	Same as study Roeden et al 2012	Not stated

Notes.
[a] PFT = problem free talk, PTC = pre-treatment change, G = goals, HF = hypothetical future, ES = exception seeking, S = scaling, C = compliments, CQ = competence questions, T = tasks, EARS= eliciting, amplifying, reinforcing and starting again

Summary and Conclusions

Research implications

This literature review has aimed to provide an overview of the evidence-base for solution-focused approaches within the context of working therapeutically with people with ID. The studies reviewed included six using SFBT with people with IDs and six applying SFC to professionals and families. Both sets of studies provide preliminary support for the benefits of SF approaches in the context of ID. In this review, in terms of SFBT, the findings were strongest for individuals in the borderline or mild ID ranges. In addition, the evidence for SFC with care staff experiencing problems in their work with clients in the moderate, severe and profound ID ranges was promising.

One descriptive case study used SFBT with an adult with mild/moderate ID and concluded that it was a helpful approach (Bliss, 2005). Another single case study with a reasonably robust methodology had positive outcomes using the SF technique, exception seeking, with a 9-year old boy who had a moderate ID (Murphy & Davis, 2005). Hence, there would be value in further case studies using SFBT with people with moderate ID to establish its effectiveness and the adaptations required for this group. Referral reasons for people to receive SFBT were diverse. This is positive in terms of its potential applicability. However, there is an argument for future research to prioritise having samples with more defined sets of problems, which would allow for identification of which problems might best be addressed using SFBT.

The identified studies in this review were valuable in terms of demonstrating the utility of SF approaches in everyday clinical practice (Campbell et al., 2014; Vereenooghe & Langdon, 2013). However, the reliance on case studies and the lack of robust methodology limits the conclusions that can be drawn regarding the efficacy of these approaches. Similar limitations have been noted in the evidence for CBT and psychodynamic therapy for people with IDs and it should be noted that the evidence base for psychological therapies for this population lags behind that for the general population (Vereenooghe & Langdon, 2013; Willner, 2005). In this context, the quality of the studies reported here is relatively good. Several authors have highlighted the barriers to conducting robust research with people with ID but they have

also outlined how such barriers can be overcome (Bhaumik et al., 2011; Hastings, 2013; Oliver et al., 2002; Vereenooghe & Langdon, 2013; Willner, 2005). Based on the findings of this review, there are a number of research implications.

Firstly, concerning study design, there is a need for further controlled studies, with larger samples and longer follow-ups. To establish efficacy, RCTs with full randomisation to SF interventions with specific treatment protocols (e.g. Roeden et al., 2011, 2014b), and CAU or another active intervention are warranted. Secondly, studies should use several different measures (descriptive, idiosyncratic and standardised) simultaneously. Similar recommendations were made in a review regarding the use of narrative therapy approaches with people with ID because it allows for assessment of changes in client-centred goals, as well as broader evaluation of psychological outcomes across the evidence-base (McParland, 2015). Thirdly, the generalisability of findings would be improved if further information regarding the assessment of ID ranges and other demographics was reported. Fourthly, efforts should be made to provide background information about service settings, in particular, any other inputs provided alongside SF interventions.

Clinical implications

The identified studies illustrated the benefits of using a SF approach that emphasises clients' and carers' strengths, competencies and empowerment (Roeden et al., 2009). This is especially important in the ID context, where experiences of deficiency and disempowerment are often a strong narrative for clients and staff (Bliss, 2005; Roeden et al., 2012). These reports provide useful information for commissioners, service managers and clinicians about how SF interventions can best be delivered in their settings. The findings indicate that services could consider offering SFBT for clients with borderline to mild ID, and possibly moderate ID, although future research is needed to confirm this. It should also be noted that based on their findings, Lloyd & Dallos (2006) advised caution around directly offering SF approaches with people with co-morbid ID and autism. The SF clinicians in these studies varied in terms of their level of experience and training and further guidance is required to enable clinicians to

make decisions regarding whether or not they have the competencies required to offer SF interventions.

The studies indicate that standard SFBT, originally developed for people without IDs, may require modification. Firstly, the reviewed studies' involvement of carers or family members in sessions and between sessions was considered helpful in supporting communication in sessions and facilitating task completion between sessions. Similar benefits have been reported in the evidence base for other psychological approaches for people with ID (Willner, 2005). Secondly, in these studies fewer techniques were used than in traditional SFBT (De Shazer et al., 2007). Studies varied in which techniques they chose to focus on, in keeping with the core assumptions of SF approaches, seeming to make these decisions based on 'what worked' for their clients (Bliss, 2005; Smith, 2005). This is consistent with general guidance for psychological interventions that emphasises the importance of creatively and flexibly tailoring techniques for people with ID, rather than rigidly adhering to protocols (RCP, 2004). Thirdly, adaptions to SF techniques to accommodate for the cognitive abilities of clients are required. These have included: using simpler language; giving sufficient time and structure to answer questions; using concrete examples when exploring exceptions; and using smaller 2-point scales and pictorial scales. Again, these adaptations are consistent with general guidance on adapting psychological techniques to accommodate for the cognitive abilities of people with IDs (Roeden et al., 2009; RCP, 2004).

One technique that consistently required adaption regardless of whether it was for individuals with IDs, their carers or their family, was the wording of the "miracle question". The studies recommend that the wording of the hypothetical future be re-phrased. The idea of a "miracle" may have been considered unhelpful because it seemed irrelevant in the context of ID or primed participants towards "wishful thinking" around the ID being absent or removed (Lloyd & Dallos, 2008). This poses the danger of locating problems within the individual. It was suggested that it be re-phrased so that it was more concrete and more focused on coping, strengths and competencies (Lloyd & Dallos, 2008).

When individuals have moderate, severe or profound ID, this review's findings suggest that SFC is more appropriate, rather than offering individual SFBT. These findings are consistent with suggestions from others that modification of protocols originally developed for the general population is more suitable for people with borderline and mild IDs than it would be for people with lower intellectual functioning (Campbell et al., 2014; Roeden et al., 2009). The techniques used with staff and family in SFC were consistent with the standard SFBT protocols and did not require additional modification, with the exception of the 'miracle questions', as noted above. SFC was most commonly provided when care staff experienced their clients' behaviour as challenging or some difficulty in the quality of their relationship (Rhodes, 2000; Roeden et al., 2012, 2014b). However, it is not clear from this review whether SFC alone is sufficient in these cases or whether additional behavioural interventions are required, which would be consistent with National Institute for Health & Clinical (NICE; 2015) guidelines for challenging behaviour. Rhodes (2000) suggested that SF approaches could provide the groundwork from which other approaches can be introduced or could be used in combination with other approaches.

Conclusions

This review has examined the evidence for SF approaches in the context of IDs. Thus far the findings are promising. They illustrate a number of potential benefits of a SF approach that focuses on creating solutions rather than analysing problems, and builds on the strengths and competencies of individuals with IDs, their families and their carers. However, the research base remains in its infancy and limits the conclusions that can be drawn about the effectiveness of SF approaches for this population. Further robust research is imminently needed if we want commissioners, service managers and clinicians to provide SF approaches in their services.

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Executive Summary

People with Chronic Fatigue Syndrome / Myalgic Encephalopathy (CFS/ME) and Irritable Bowel Syndrome (IBS) experience high levels of disability and impaired quality of life. Both conditions are also associated with significant costs to the healthcare system. CFS/ME results in a marked loss of energy and a prolonged recovery period following mental or physical exertion. IBS is characterised by abdominal pain, abdominal bloating, constipation and diarrhoea.

While several physical factors have been found to be associated with CFS/ME and IBS, as of yet no definitive medical cause for them has been identified. For that reason, they are considered “medically unexplained symptoms” (MUS). This term is controversial because it can be seen as implying that they are caused by psychological factors. Hence, it is important to note that this study did not take this position. Instead, it recognised that psychological factors can impact how people experience health problems, whether these problems have a known medical cause or not. For example, recent research has shown this to be the case for a number of long-term health conditions (e.g. Multiple Sclerosis, Parkinson’s Disease and Type 2 Diabetes). Also, service-user groups prefer the term Persistent Physical Symptoms (PPS) without a known medical cause rather than MUS.

According to the Cognitive Behavioural Therapy (CBT) model of PPS, there is a complex range of cognitive, behavioural, emotional, social and physiological factors involved. Each of these factors interacts and forms 'vicious cycles’ that maintain and exacerbate symptoms. In CBT, the person is helped to understand, test and dismantle these vicious cycles. The focus of the present study was cognitive (e.g. beliefs about the cause, consequences and management of symptoms) and behavioural (e.g. withdrawal, avoidance and safety-seeking) factors, as research has separately investigated these factors in CFS/ME and IBS and they are usually the initial targets of CBT treatment.

Despite the high rate of comorbidity between CFS/ME and IBS, studies have not directly compared them to establish where the similarities (i.e.

transdiagnostic) and differences (i.e. disorder-specific) lie regarding these cognitive and behavioural factors. Identifying this would have significant implications for how CBT interventions are tailored to CFS/ME and IBS. Hence, this study aimed to compare people with CFS/ME and IBS in terms of their beliefs about symptoms and behavioural responses to symptoms. This was achieved by comparing 21 people with CFS/ME, 40 with IBS, 17 with both of these conditions (co-morbid), and 65 with neither of these conditions (i.e. healthy controls).

Each participant completed online questionnaires. They measured general psychological characteristics (depression, generalised anxiety, health anxiety, functional impairment and mental defeat) using well-validated measures. Novel scales were developed to measure general beliefs and behaviours (transdiagnostic), as well as to measure beliefs and behaviours that were specific to fatigue and gastrointestinal symptoms (disorder-specific). As these scales were newly developed, an analysis was completed to check that the items of each scale produced similar results. All were found to have good internal consistency. Examples of the different items in the beliefs and behaviours scale are provided below.

First, the findings showed that compared with healthy controls, all of the clinical groups had higher levels of psychological distress and impairment, and the CFS/ME and co-morbid groups had the highest levels.

Second, the findings showed that the clinical groups reported more transdiagnostic beliefs (e.g. ‘I should be able to control my symptoms’, ‘It’s embarrassing when my symptoms flare up’) and behaviours (e.g. ‘I ask for reassurance about my symptoms’, ‘I avoid attending social activities’) than healthy controls. Given the high co-morbidity found between CFS/ME and IBS, it is not surprising that common factors were identified. Nevertheless, the CFS/ME and co-morbid groups reported more such transdiagnostic beliefs than the IBS group.

Third, the findings showed that the CFS/ME and IBS groups differed in terms of the disorder-specific beliefs and behaviours. For instance, the CFS/ME

and co-morbid group endorsed more beliefs (e.g. ‘my fatigue problems are caused by over-activity’, ‘my fatigue problems are caused by stress’) and behaviours (e.g. ‘There were certain things I needed to do that I didn’t do’, “Most of that I did was to escape from or avoid something unpleasant’) relating to fatigue than the IBS or healthy control groups. Similarly, the IBS group endorsed beliefs (e.g. ‘I worry about losing control of my bowels in public’, ‘It’s embarrassing when I keep going to the bathroom’) and behaviours (e.g. ‘I weat baggy clothing when my stomach feels bloated or distended) that are relevant to gastrointestinal symptoms, but the CFS/ME and healthy control groups did not.

To the author’s knowledge, this study is the first to compare people with CFS/ME and IBS in relation to their beliefs about symptoms and behavioural responses to symptoms. Overall these findings indicate that there are both similar and different beliefs and behaviours in CFS/ME and IBS. This has important implications for how CBT interventions are delivered. It suggests that it may be helpful to provide a modular CBT approach for people with PPS generally, and CFS/ME and IBS specifically, whereby therapy would start by addressing the common features of PPS and become more tailored to the patient’s specific problem as therapy progresses.

Reflective Narrative

Throughout the course, I have completed three research projects: the main research project (MRP), a service improvement project (SIP) and a literature review (LR). I have also written up five case studies. Completing doctorate level research along clinical placements and teaching has been challenging and at times it has seemed impossible, but I believe it has been it has all been worthwhile. As a scientist-practitioner, I believe it is important to contribute actively to the evidence-base. There are many different ways that this can be done but I have found that I am most enthusiastic and invested in research when it originates directly from a need in clinical practice and when its findings can have immediate benefits for service-users, their families and clinicians. This interest is reflected in my choice of research projects.

Main Research Project

My idea for my MRP stemmed from my personal and clinical experience. Years previously, I had suffered from IBS and found CBT strategies very helpful for managing it. A few years later, I was involved with delivering psycho-educational CBT courses for IBS and CFS/ME, in an Improving Access to Psychological Therapies (IAPT) service. Changes on pre and post outcome measures and positive qualitative feedback indicated that people found the courses helpful. I noticed that the materials drew directly from other generic depression and anxiety courses I was running. This made me curious about which adaptations to the CBT model were or were not required for these syndromes and what implications this would have for clinical practice.

At the 2013 course research conference, I spoke with Paul about my interest in this area. He told me that he was involved in setting up a new CBT psychology service for people with Medically Unexplained Symptoms (MUS), in collaboration with an IAPT service and GP practices in Gloucester. They were initially running a feasibility study to demonstrate the possible advantages of this service being commissioned. Paul agreed to supervise my project, which would investigate cognitive-behavioural trans-diagnostic and disorder-specific features of CFS/ME and IBS, with the hope that the findings would help to inform the CBT treatment programmes for the new service. I was very excited

about the opportunity to complete research that could have a direct impact on clinical practice.

This was a brilliant opportunity for some additional reasons. I was able to attend some of the beginning meetings between the University of Bath researchers, the IAPT service lead and GP commissioners, from which I gained insights into the processes behind service commissioning and set-up. I was also able to make some suggestions, one of which was that they consider inviting a person with personal experience of Persistent Physical Symptoms (PPS) without known medical cause to advise on how the service could best meet their needs. Service-user groups prefer the term PPS rather than MUS. Unfortunately, due to clinical placement commitments, I was unable to continue to attend meetings but I was happy to hear that a person with personal experience, who is involved in a local group called "hidden illnesses" is now actively consulting with the group. This took some months to put in place, which unfortunately meant I wasn't able to ask for their opinions on my study design before I had to apply for NHS ethics. However, I have since contacted the group and asked if they would be interested in giving feedback on my report of the findings once it has been completed, which they said they would be interested in doing. Another anticipated benefit of being linked with the PPS service feasibility project was that it would help with recruitment regarding access to participants and support from the clinicians in those services. Unfortunately, this did not turn out to be the case. The feasibility project was delayed for reasons outside of my control and my project needed to go ahead as planned otherwise I would not meet the deadlines.

Consequently, I needed to refocus my participant recruitment efforts elsewhere. Luckily, I had already started to make links with other IAPT, specialist CFS/ME and gastroenterology services in the area. The specialist NBT CFS/ME service was very supportive and invited me to the first sessions of their psycho-educational courses to introduce my research. LIFT Psychology also helped in advertising the research at their services bases, but, unfortunately, the number of courses they had been running for CFS/ME and IBS had recently reduced. At first, some of the local gastroenterology services showed interest in the project but then did not respond to requests for further

discussion about how to implement it at their services and unfortunately other services did not respond to our attempts to contact.

Overall numbers recruited from services remained low and I decided to put most of my efforts into recruitment via social media, which was yielding the highest response rate. I remember being a little reluctant to do this as I am not an avid user of social media, at the best of times, and I had no experience of using for professional purposes. It was also at this stage that I became more conscious of the controversy around doing psychological research in the area of long-term health conditions that do not have a known medical cause, especially concerning ME/CFS. When looking at some of the posts on social media, I was disheartened to hear some of the dissatisfactory and sometimes shaming experiences people had had with healthcare professionals. I also noticed there were themes around people receiving messages that their symptoms were "all in their heads". Some described how they felt that psychological research reinforced these ideas and detracted from research to investigating medical causes and treatment for their disabling symptoms.

For this reason, I currently have mixed feelings about my MRP. I strongly believe it is important to listen to the views of people with personal experience and some are in CFS/ME community are very vocal in their view that psychological research is at best unhelpful and at worst damaging. At the same time, I am also aware of many people within these communities that are actively calling for further research from the medical and psychological disciplines. Additionally, my personal and clinical experience tell me that, at least for some, psychological interventions can be very helpful, just as they are for other physical health conditions, where there are known medical causes and treatments, such as oncology, multiple sclerosis and arthritis. Perhaps to onus is on psychologists to more actively seek open dialogue with those who are concerned about this type of research and hopefully going forward we can then do a better job of addressing their concerns. Personally, I believe that research in the area of PPS will only be fruitful when all stakeholders are invited to the table and can set the research agendas collaboratively. I am presenting my findings at the 2016 BABCP conference, which has an audience of

psychological professionals but I also plan to seek feedback from other stakeholders, such as the "hidden illness" group.

Service Improvement Project

The opportunity to collaborate with OCD-UK arose at the course's 2013 research conference. OCD-UK is a charity, solely run by people with personal experience of OCD and it works towards its vision of a time when everyone affected by OCD will receive the highest quality evidence-based care. OCD-UK had discussed with Professor Paul Salkovskis their interest in evaluating and developing their conferences. Paul suggested it would make a good SIP. I was immediately interested. I was particularly drawn to the idea of collaborating with a third sector organisation that has a positive impact on people whose lives are affected by OCD and also the potential to enhance clinical NHS-practice. Most of my previous research had related to service evaluation in NHS-based services, which I had found very rewarding, but this would be a new area for me.

I was initially introduced to Ashley Fulwood (Director) and Dr Charlotte Rowe (Conference team member), by Paul. We held regular Skype meetings, along with another trainee, who was collaborating with them on another project. OCD-UK's identity of being service-user run was of great value to members. Professionals had previously been invited to speak at conferences, but this project marked the first time of them being invited to help shape conferences. I was conscious that some members had reservations about this. It was key that we formed good working relationships from the outset and in our early meetings I asked about the background of the organisation, as well as their hopes and any concerns they had about involving professionals. Through this consultation, we identified that while the previous OCD-UK Members conferences were well attended and received favourable feedback, OCD-UK wanted to gather more meaningful data about any change in attendees' understanding and beliefs about OCD. After discussions with OCD-UK, we agreed that the Patients Beliefs Scale about OCD, developed by Blake Stobie (a Ph.D. student of Paul's) could be usefully adapted for the conference.

Following ethical approval from the University of Bath, we headed off to the OCD-UK Nottingham conference. This was without a doubt the highlight of the whole project. Attendees were incredibly friendly and showed interest in the project. The quality of the presentations was brilliant. We heard from researchers in the field but also personal stories from people with first-hand experience of OCD and treatment. The conference was very successful and received favourable feedback. It was inspiring to see the changes in levels of confidence and beliefs about OCD on the pre and post questionnaires. In the space of a day, attendees went from holding the belief that OCD was a biological disease to believing in the benefits of psychological intervention and the possibility of recovery.

For me, the biggest potential of conferences like these was realised at the coffee breaks, where you could see everyone talking together about their experience of OCD, whether it was from personal experience or their clinical practice. There was no sense of "us and them" that I could see. I was inspired by this and believe it is the way forward for mental health services. This experience likely influenced my later decisions to become involved in the People with Personal Experience Committee for the doctorate. Going forward, I hope to continue working with people with personal experience to improve services and shape research. I will be attending the British Association for Behavioural and Cognitive Psychotherapies (BABCP) 2016 conference with a poster presentation of the findings. I am looking forward to this and hope it might inspire other clinicians to think about how they can work with service-user groups to improve the lives of people with personal experience of physical and psychological difficulties.

Critical Review of Literature

The topic of my LR changed four times. It was hard to identify a topic that captured my research interests, that had not been previously completed and that was feasible (i.e. not too many or too few articles). My first idea was to look at mindfulness for voice hearing. I had a personal interest in mindfulness for many years and on my first placement, I incorporated it into the work with some clients who heard voices. I was surprised by the lack of consistent guidance in the literature regarding using mindfulness for this population. My proposal for

this LR was passed but I found that I didn't make much headway with it, possibly because I had since left my first placement and voice hearing work was less relevant in subsequent placements. More likely, was that mindfulness was an important personal practice for me and a part of me wanted to keep it separate from the course.

We received teaching on psychologically informed health interventions for people with intellectual disabilities from Dr Cathy Randle-Philips. My interest was immediately piqued. For some time, I had been interested in the beliefs people hold about their health and illness. Some of this interest came from my previous training and my clinical experience working in primary care, where I saw the link between the mind and body play out. More recently, on my intellectual disabilities placement, I had been disheartened by the unacceptable levels of poor physical health seen in many of the service's clients. Additionally, the paucity of research regarding psychology informed health interventions for this population group, in comparison with that for the general population, did not sit well with me. I approached Cathy to discuss the options for a literature review. It turned out that this was quite timely as she was involved with a research group who were developing a psychologically informed intervention to help people with intellectual disabilities manage diabetes. We developed a list of aims and a search strategy for a LR investigating health beliefs in individuals with intellectual disabilities, with the hope that this would inform the work of her research group. Coincidently, a LR with pretty much the same aims and search strategy was published a few weeks later by another author. We didn't believe that any tweaking of our LR would make it a valuable addition to the literature base.

Cathy and I entered into discussions again. She told me that her research group had decided that a motivational interviewing approach would be used for their diabetes intervention. We agreed that a review of its wider applications with people with intellectual disabilities would be helpful. I was quite happy with this change in LR focus, as I had used motivational interviewing a lot in previous work but never with this population and therefore, thought it would be interesting. My enthusiasm waned when the initial search yielded a very large number (near 1,000) of articles to be screened. Unexpectantly, only six

met the criteria. We worried that this would not be considered enough articles. We went back and forth about whether we could include other articles that partly met the inclusion criteria. On reflection, we agreed that we could not do this without 'fudging' the search criteria, which would undermine the LR findings. In a nutshell, it was back to the drawing board. Although I felt very disheartened by this as a considerable amount of time had already gone into it and we were only a few months away from hand-in, I believed it was the right decision.

I remembered that I had used another brief intervention, solution-focused brief therapy, with people with intellectual disabilities and had found some case studies particularly helpful but was not aware of any clear clinical or research guidance on using it with this population. Hence, I suggested that we change the search to examine the use of solution-focused approaches in the context intellectual disabilities. The idea of researching a systemic approach appealed as I had started to use it more and more in my other clinical work and I didn't feel this had been reflected in my research projects and case studies yet. Luckily, the search yielded a manageable number of articles to screen and for the most part, they were very enjoyable to read. Despite this, I completely underestimated the amount of time required to synthase all of the information presented in a clear and coherent way. Personally, I found only have an hour here and there to do this added to the difficulty, as each time I approached the articles, it felt like I was starting again. Hopefully, clinicians will find the finished review helpful and it will lead to more research in the area. I plan to share the findings with an intellectual disabilities research group that Cathy has set-up recently at the University.

Case Studies

Throughout training I have completed five case studies; each represented a piece of work from my different clinical placements. I found that I choose cases studies based on which case would be the easiest to write up in terms of meeting the requirements of the course. Four were required to include cognitive-behavioural interventions, with a minimum of five sessions and CTSR passed. Continuous use of valid and reliable measures was encouraged and required for two single case designs. I can see the value of these requirements, especially since completing my LR, which highlighted the importance of robust

case study methodologies. However, I sometimes felt this dissuaded me from writing up other pieces of work that had a clinical heuristic value and would have been helpful for my learning needs. Personally, I found the 'academic' side of writing up case studies challenging and am not particularly proud of any of the write-ups. I am much prouder of the 'scientist-practitioner' and ‘therapeutic relationship' processes behind those pieces of work but I feel I struggled to get these across in the write-ups. Going forward I plan to continue to consult the existing evidence-base, to form and revise hypotheses (i.e. formulation), to evaluate my approach, to remain curious about the implications for my clinical practice and to consider future research implications; and perhaps with time, I will get better at the write-up part.

Summary

The course encouraged us to consider a breadth of research topics, rather than focusing on a single research area. I took this advice on board and had a range of different research topics. I found this interesting and now that I am at a stage of considering applications for post-training positions I can see the value of having a broader number of research interests. I am actively seeking positions where I will have opportunities to complete service evaluation and development projects, in collaboration with people with personal experience. I've learned through my doctorate that I am most interested and passionate about this type of research. Also, I hope in the future that I will be able to act as a regional supervisor on trainee clinical psychologist research projects.

Main Research Project Appendices

Appendix A: Author instructions for the Journal of Psychosomatic Research
GUIDE FOR AUTHORS

Your Paper Your Way

We now differentiate between the requirements for new and revised submissions. You may choose to submit your manuscript as a single Word or PDF file to be used in the refereeing process. Only when your paper is at the revision stage, will you be requested to put your paper in to a 'correct format' for acceptance and provide the items required for the publication of your article.
To find out more, please visit the Preparation section below.

INTRODUCTION

Types of article

Full Length Papers
Full length research papers will not normally be more than 4000 words in length (Introduction through Discussion) and will preferably be shorter. Submission of a paper to the Journal of Psychosomatic Research will be held to imply that it represents original research not previously published (except in the form of an abstract or preliminary report), that it is not being considered for publication elsewhere, and that if accepted by the Journal of Psychosomatic Research it will not be published elsewhere in the same form in any language without the consent of the Publisher. Major papers of topical content will be given priority in publication. **Please note that this journal does not publish animal studies.**

Short Reports
The journal welcomes short reports, which may be either preliminary communications or brief accounts of original research. Short Reports must not exceed 1500 words and should include no more than 2 tables and 30 references. The journal does not publish case reports.

Editorials
The Editors welcome suggestions for editorials which give personal and topical views on subjects within the journal's area of interest. They should not normally exceed 1500 words, excluding references and should have no more than 20 references.

Review Articles
Review papers are normally 4000-5000 words (Introduction through Discussion). Authors are advised to consult one of the Editors with an outline before submitting a review.

Letters to the Editors
These normally refer to articles previously published in the journal. The Editors are also willing to consider letters on subjects of direct relevance to the journal's interest, including research letters. Letters should not exceed 1000 words, including references. Where appropriate, they should begin with a reference to the published article that is the subject of the letter. Research letters should be submitted as 'Letters to the Editors'

Special Articles
These may be invited by an editor or submitted after discussion with an editor. Special articles are designed to provide an analysis of a topic of particular interest to readers of the journal and are more extensive in scope than an editorial. They should not primarily be a commentary on an article previously published in the journal, which would be better addressed in a letter or editorial.

Other Papers
The Editors welcome suggestions for other types of papers, such as conference reports, accounts of major research in progress and interviews with senior research workers. These should not be submitted without prior consultation with an editor.

Contributions for the European Association for Psychosomatic Medicine (EAPM) pages
These should generally not exceed 1000 words, excluding references. Contributions for the EAPM pages must not have an abstract. Topics covered in these pages should be of interest to EAPM members and may be focused on innovations and developments in clinical services in specific European countries, updates on important developments in specific European countries, contributions related to the EAPM, papers focusing on historic topics, etc. Results of scientific research should not be submitted to the EAPM pages, since these require peer-review. Contributions for the EAPM pages are not peer-reviewed but subject to editorial approval. EAPM In case of doubt about the suitability of a subject, please contact the European editor or the EAPM section editor at jpsychores@elsevier.com

Contact details for submission
Journal of Psychosomatic Research

Regardless of how you choose to publish your article, the journal will apply the same peer review criteria and acceptance standards.

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For non-commercial purposes, lets others distribute and copy the article, and to include in a collective work (such as an anthology), as long as they credit the author(s) and provided they do not alter or modify the article.

The open access publication fee for this journal is **USD 3300**, excluding taxes. Learn more about Elsevier's pricing policy: https://www.elsevier.com/openaccesspricing.

Green open access
Authors can share their research in a variety of different ways and Elsevier has a number of green open access options available. We recommend authors see our green open access page for further information. Authors can also self-archive their manuscripts immediately and enable public access from their institution's repository after an embargo period. This is the version that has been accepted for publication and which typically includes author-incorporated changes suggested during submission, peer review and in editor-author communications. Embargo period: For subscription articles, an appropriate amount of time is needed for journals to deliver value to subscribing customers before an article becomes freely available to the public. This is the embargo period and it begins from the date the article is formally published online in its final and fully citable form.

This journal has an embargo period of 12 months.

Elsevier Publishing Campus
The Elsevier Publishing Campus (www.publishingcampus.com) is an online platform offering free lectures, interactive training and professional advice to support you in publishing your research. The College of Skills training offers modules on how to prepare, write and structure your article and explains how editors will look at your paper when it is submitted for publication. Use these resources, and more, to ensure that your submission will be the best that you can make it.

Language (usage and editing services)
Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop.

Submissions
The Journal of Psychosomatic Research utilizes a web-based submission and peer review system. Authors should submit their manuscripts, with figures and tables, electronically at the journal Web site: http://ees.elsevier.com/jpsychores . Complete instructions are available on the Web site.

The journal reviews all material that it receives. Approximately 50% of manuscripts are rejected after pre-review by an editor, typically after consultation with another member of the editorial staff or an external peer reviewer. This is done so as to allow authors whose manuscripts would almost certainly be rejected after peer review to submit the work elsewhere with as little delay as possible. Common reasons for rejection at this stage are insufficient originality, low priority of interest to the journal and clear quality deficits. We attempt to reach an initial decision on all articles that go through full peer review within 90 days of submission. Approximately 25% of submitted manuscripts are ultimately accepted for publication.

PREPARATION

Manuscripts should conform to the uniform requirements known as the 'Vancouver style' (International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to biomedical journals. N Engl J Med 1997; 336:309-315). The Editors and Referees attach considerable importance to a succinct and lucid prose style and well organized tables. Authors whose native language is not English are advised to seek help before submission. Statistical procedures should be clearly explained.Manuscripts should conform to the uniform requirements known as the 'Vancouver style' (International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to biomedical journals. N Engl J Med 1997; 336:309-315). The Editors and

Referees attach considerable importance to a succinct and lucid prose style and well organized tables. Authors whose native language is not English are advised to seek help before submission. Statistical procedures should be clearly explained.

NEW SUBMISSIONS

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.
As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or lay-out that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

References
There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting requirements
There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.
If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.
Divide the article into clearly defined sections.

Figures and tables embedded in text
Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file.

REVISED SUBMISSIONS

Use of word processing software
Regardless of the file format of the original submission, at revision you must provide us with an editable file of the entire article. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). See also the section on Electronic artwork.
To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Cover letter
Each manuscript should be accompanied by a Cover Letter. In addition to a brief description of the article being submitted and its relevance to likely readers of the journal, the Cover Letter should include a statement that (1)authors of this article had access to all study data, are responsible for all contents of the article, and had authority over manuscript preparation and the decision to submit the manuscript for publication, (2) that all listed authors have approved of the submission of the manuscript to the journal, and (3) an explanation of the relationship of the submitted paper to any other published, submitted or proposed papers reporting the same or overlapping data. You may submit the completed letter online.

Title Page
This should contain (a) the title of the article; (b) a short running head; (c) name of department where the work was conducted; (d) names of the each author with highest academic degree; (e) name, address, phone and fax of author responsible for correspondence and to whom requests for reprints should be addressed.

Structured Abstract
This should be subdivided under the headings **Objective, Methods, Results, and Conclusion** and should not exceed 250 words.

Keywords
Up to six keywords should be listed in alphabetical order after the abstract. These terms should optimally characterize the paper to facilitate choice of peer reviewers.

Article Structure
The text should be divided into sections with main headings: Introduction, Method, Results and Discussion and, in total, these sections should not normally be greater than 4000 words in length.

Acknowledments
Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. Acknowledgements must include mention of any source of funding outside the basic funding of the host institution (see *Role of the funding source* above). List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Tables
Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.Each should be on a separate sheet, numbered consecutively in Roman numerals.

Figures
Each should be on a separate sheet, and numbered consecutively. Captions should be on a separate sheet. The number of illustrations should be kept to a minimum. Colour illustrations are not normally acceptable. Authors may be asked to support the costs of colour reproduction.

Competing Interest Statement
All manuscripts should include a competing interests declaration that should be in the following format:

'All authors have completed the Unified Competing Interest form at http://www.icmje.org/coi_disclosure.pdf and declare that(1)[authors] received support from [name of company or other competing interest] for the submitted work;(2)[authors] have [specify relationships] with [name of companies or other competing interests] in the past three years that could be perceived to constitute a conflict of interest;(3)spouses, partners, or children of [authors] have [specified] financial relationships that may be relevant to the submitted work; and(4)[authors] have [specify type of relationship] non-financial interests that may be relevant to the submitted work. 'If there are no competing interests to report, the authors should state, 'The authors have no competing interests to report'.

Appendices
If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Graphical abstract
Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.
Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images and in accordance with all technical requirements: Illustration Service.

Highlights
Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view example Highlights on our information site.

Appendix B: Ethical approval forms

Re: Ethics 15-234

psychology-ethics

Tue 08/12/2015 22:47

To:Hazel Carrick <H.Carrick@ bath.ac.uk>;

Dear Hazel,

Thank you for submitting this amendment request. We agree that this is minor, and is thus approved by Chair's Action.

Best wishes,
Dr Michael Proulx
Chair, Psychology Research Ethics Committee

From: Hazel Carrick
Sent: 04 December 2015 12:09
To: psychology-ethics
Subject: Re: Ethics 15-234

Dear Dr Michael J Proulx,

We would like to request your approval to a minor amendment to my project.

REC reference: 15/WA/0298.

IRAS Project ID Number:171274

University of Bath Psychology Ethics Reference Number: 15-234

We consider this a minor amendment as it does not significantly affect the wellbeing of participants or constitute a significant change to the study protocol. We would like to add three background questions to the questionnaire. Please find attached an update version of the questionnaire (Battery_V2_01 12 2015). The three questions are as follows:

1. Can you tell us how you heard about this research? (please tick)
NHS service I was attending
A website, which supports people with IBS or Chronic Fatigue Syndrome/ME
General advertisement e.g. Online social media, posters
Other (please state):_____

9. Can you tell us if you have a diagnosis of any medical conditions? If yes, please provide details below.

10. Can you tell us if you have any psychological or mental health conditions? If yes, please provide details below.

I would appreciate any help with this,

Many thanks,
Hazel Carrick
Clinical Psychologist in Training
University of Bath

From: psychology-ethics
Sent: 06 November 2015 08:16
To: Hazel Carrick
Subject: Ethics 15-234

Dear Hazel Carrick,

Reference Number 15-234: Psychological factors in chronic fatigue syndrome/myalgic encephalomyelitis and irritable bowel syndrome

The ethics committee have considered your ethics proposal for the study above and have given it full ethical approval.

Best wishes with your research.

Dr Michael J Proulx
Chair, Psychology Research Ethics Committee

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

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Carmarthen
SA31 3WY

Tel: 01267 225045
Email: sue.byng@wales.nhs.uk

Ms Hazel Carrick
Clinical Psychology Unit and Research Centre
University of Bath
Bath
BA2 7AY

9 December 2015

Dear Ms Carrick

Study title:	**Psychological Factors in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis & Irritable Bowel Syndrome**
REC reference:	**15/WA/0298**
Amendment number:	**1 (minor)**
Amendment date:	**09 December 2015**
IRAS project ID:	**171274**

Thank you for your email of 9 December 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Non-validated questionnaire	2	01 December 2015
Email from Chief Investigator – addition of 3 background questions to the Questionnaire		09 December 2015
Email from sponsor		09 December 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/WA/0298:	Please quote this number on all correspondence

Yours sincerely

Sue Byng

Ms Sue Byng
REC Manager

Email: sue.byng@wales.nhs.uk
Copy to: *Mr Mark Walker, Gloucestershire Hospitals Foundation NHS Trust*
Professor Jane Millar

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

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Ms Hazel Carrick
Clinical Psychology Unit and Research Centre
University of Bath
Bath
BA2 7AY

9 September 2015

Dear Ms Carrick

Study title: **Psychological Factors in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis & Irritable Bowel Syndrome**
REC reference: **15/WA/0298**
IRAS project ID: **171274**

I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 27 August 2015.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Information Sheet – NHS Services	2	05 September 2015
Participant Information Sheet – Community Samples	2	05 September 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Participant Information Sheet – NHS Services	2	05 September 2015
Participant Information Sheet – Community Samples	2	05 September 2015
IRAS Checklist XML [Checklist_31072015]		31 July 2015
Letter from sponsor		21 July 2015
Letters of invitation to participant	1	03 July 2015
Screening form for CFS/ME participants	1	21 June 2015
Advertisements for CFS/ME & IBS	1	18 June 2015
Advertisement for healthy controls	1	18 June 2015
Consent to contact form	1	18 June 2015
Consent form for NHS sample	1	18 June 2015
Consent form for community sample	1	18 June 2015

Academic supervisor CV Dr Paul Salkovskis	Unsigned	Undated
Academic supervisor CV Josie Millar	Unsigned	Undated
Questionnaire Battery	1	08 July 2015
University of Bath insurance documents Part 1		01 August 2014
University of Bath insurance documents Part 2		01 August 2014
REC Application Form [REC_Form_31072015]		31 July 2015
Scientific critique report – letter from Research Tutor, University of Bath		16 July 2015
Research protocol	1	03 June 2015
Summary CV for Chief Investigator (CI) Ms Hazel Carrick	Unsigned	Undated

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/WA/0298	**Please quote this number on all correspondence**

Yours sincerely

Ms Sue Byng
REC Manager

Copy to: *Professor Jane Millar*
Mark Walker, 2gether NHS Foundation Trust

Appendix C: Further details regarding participant inclusion and exclusion criteria

Some participants scored in the caseness ranges for conditions that they had not self-identified as having. After discussion with my supervisor and the statistics department at the University of Bath, it was agreed that these participants would not be excluded on this basis, as some overlap in CFS/ME and IBS symptomology would be expected and not necessarily indicate the "true" presence of the condition. However, it was agreed that data trimming was required to establish that the groups were distinct from each other. Hence, participants who met caseness on the CF-Scale and scored more than 2 standard deviations above the mean (within their group) but had not self-identified as having CFS/ME were excluded. The same procedure was followed for those who met caseness on the IBS-SSS and scored more than 2 standard deviations above the mean (within their group) but had not self-identified as having IBS. In the CFS/ME group, one participant was removed because they scored above 290.42 on the IBS-SSS. In the IBS group, three participants were removed because they scored 10 or above (rounded down from 10.34) on the CF-Scale. Four participants were removed from the HC group because they scored above 6.62 on the CF-Scale (bi-modal scoring) and a further two participants were removed for scoring above 117.63 on the IBS-SSS. Final sample groups were: 21 CFS/ME only, 40 IBS only, 17 comorbid, and 65 HC.

Appendix D: Transdiagnostic and disorder-specific measures

Beliefs about Physical Symptoms

We would like to know more about your personal beliefs about any physical symptoms you may experience. As people are very different, there are no right or wrong responses for these questions. We are most interested in your own beliefs about your physical symptoms rather than what others including doctors or family may have suggested to you. Please indicate how much you agree or disagree with the following statements about physical symptoms you may experience by circling a number on the scale. Please circle only one box per line.

1. My symptoms can be caused by over-activity:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

2. It is important to avoid exercise when my symptoms flare up:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

3. Doing less activity than usual helps to improve my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

4. My symptoms can be caused by stress:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

5. I can't function normally when I have symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

6. The pain I experience from symptoms will never go away:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

7. My symptoms interfere with how I feel about myself:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

8. It's embarrassing when my symptoms flare up:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

9. I should be able to control my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

10. I can't do my daily activities because it will make my symptoms worse:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

11. When my symptoms are bad I am afraid I won't be able to control my emotions:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

12. If I don't hold back on my daily activities my symptoms will cripple me:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

13. If others notice my symptoms they will think I am weak or there is something wrong with me:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

14. My symptoms cause difficulties for those who are close to me:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

15. There is very little that can be done to improve my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

16. My symptoms don't make any sense to me:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

17. My symptoms will get better by self-management:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

18. My symptoms have a psychological cause:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

19. My symptoms will not get better without medical treatment:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

20. When I think about my symptoms I get upset:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

21. When I think about my symptoms I get angry:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

22. My symptoms will get better with treatment:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

Physical Symptoms and Behaviour

This questionnaire is about how physical symptoms may have impacted your behaviour. As people are very different, there are no right or wrong responses for these questions. Please indicate how much you agree or disagree with the following statements about physical symptoms by circling a number on the scale. Please circle only one box per line.

1. I eat specific foods/drink specific beverages to help me to manage my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

2. I avoid certain food/beverages to help me manage my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

3. I ask for reassurance about my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

4. I am constantly aware of my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

5. I spend a long time thinking over and over about my problems:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

6. I avoid attending social activities because of my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

7. I would like to achieve things at work/school, but I have to set limits because of my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

8. In order to avoid feelings of disappointment, I just try not to set myself goals or make plans:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

9. Rather than try new activities, I tend to stick with the things I know:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

10. I do not answer the phone in case people are calling with social invitations:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

11. I quit activities that challenge me too much:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

12. While I know I should make decisions about my personal relationships, I just let things go on as they are:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

13. Because of my symptoms I avoid trying new activities that hold the potential for failure:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

14. I am constantly trying to find a cause or a solution for my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

15. I frequently attend the GP:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

16. I avoid the GP:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

17. I avoid talking about my symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

18. When my symptoms are not as bad, I make the most of it and do as many things as I can (e.g. work, hobbies, socialising):											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

Beliefs about Fatigue Symptoms

We would like to know more about your beliefs about fatigue symptoms. Please indicate to what extent you personally agree or disagree with each statement by circling a number on the scale. Please circle only one box per line.

1. My fatigue problems can be caused by over-activity:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

2. It is important to avoid exercise when I feel tired:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

3. I believe that my fatigue problems are caused by a virus or infection:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

4. Doing less activity than usual helps to improve my fatigue problems:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

5. My fatigue problems can be caused by failing to get enough rest:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

6. Doing exercise is harmful to me:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

7. My fatigue problems can be caused by stress:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

8. I should avoid doing physical activity											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

Beliefs about Gastrointestinal Problems

We would like to know more about your beliefs about gastrointestinal problems (i.e. constipation, diarrhoea, stomach cramps/pain and feeling sick). Please indicate to what extent you personally agree or disagree with each statement by circling a number on the scale. Please circle only one box per line.

1. I worry I won't get to the bathroom in time when I have gastrointestinal symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

2. If I have a bowel accident in public other people will notice and be disgusted:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

3. I can't function normally when I have gastrointestinal symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

4. The pain I experience from gastrointestinal symptoms will never go away:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

5. Gastrointestinal symptoms interfere with how I feel about myself:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

6. It's embarrassing when I keep going to the bathroom:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

7. I hate making a fool out of myself because of my gastrointestinal symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

8. Others think there is something wrong with me when I make frequent trips to the bathroom:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

9. I worry about losing control of my bowels in public:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

10. If I don't get home when I have gastrointestinal symptoms I will have an accident in public:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

11. If I have gastrointestinal symptoms in public others will notice and be disgusted:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

12. If I don't plan ahead to manage my gastrointestinal symptoms then I will have a bowel accident											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

13. I should be able to control my gastrointestinal symptoms:											
Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree

Fatigue Symptoms and Behaviour

This questionnaire is about how fatigue symptoms (i.e. chronic tiredness, fatigue & muscle problems) may have impacted your behaviour. Please read each statement carefully and then rate the extent to which these statements applied to you over the last week. Please circle only one box per line.

	Not at all		**A little**		**A lot**		**Compl-etely**
1. There were certain things I needed to do that I didn't do.	0	1	2	3	4	5	6
2. I am content with the types and amount of things I did.	0	1	2	3	4	5	6
3. I engaged in many different activities.	0	1	2	3	4	5	6
4. I made good decisions about what kind of activities and/or situations I put myself in.	0	1	2	3	4	5	6
5. I was an active person and accomplished the goals I set out to do.	0	1	2	3	4	5	6
6. Most of what I did was to escape from or avoid something unpleasant.	0	1	2	3	4	5	6
7. I spent a long time thinking over and over about my problems.	0	1	2	3	4	5	6
8. I engaged in activities that would distract me from feeling bad.	0	1	2	3	4	5	6
9. I did things that were enjoyable.	0	1	2	3	4	5	6

Gastrointestinal Problems and Behaviour
We would like to know more about how gastrointestinal problems (i.e. constipation, diarrhoea, stomach cramps/pain and feeling sick) may have impacted your behaviour. Please read each statement carefully and then rate the extent to which these statements applied to you over the last week.

	Never						**Always**
1. I eat specific foods to help me open my bowels more.	1	2	3	4	5	6	7
2. I eat specific foods to help me open my bowels less.	1	2	3	4	5	6	7
3. After opening my bowels I check for blood.	1	2	3	4	5	6	7
4. After opening my bowels I check my stool for abnormalities.	1	2	3	4	5	6	7
5. I spend more time on the toilet that I ideally would like.	1	2	3	4	5	6	7
6. I often go to the toilet to open my bowels and then do not pass anything.	1	2	3	4	5	6	7
7. I often got to the toilet to pass water and find I open my bowels.	1	2	3	4	5	6	7
8. I avoid exercise when I have stomach pains.	1	2	3	4	5	6	7
9. I avoid certain foods when I have bowel problems.	1	2	3	4	5	6	7
10. I wear baggy clothing when my stomach feels bloated or distended.	1	2	3	4	5	6	7

11. I carry other items (e.g. wet wipes, sanitary towels, spare underwear) in case my symptoms flare up.	1	2	3	4	5	6	7
12. I avoid sex in case my symptoms flare up (and causes embarrassment).	1	2	3	4	5	6	7
13. I ask for reassurance about my gastrointestinal problems.	1	2	3	4	5	6	7
14. I avoid certain foods (e.g. dairy products, spicy food, wheat) because of my gastrointestinal problems.	1	2	3	4	5	6	7
15. After I open my bowels I wipe more than I would like.	1	2	3	4	5	6	7
16. I am constantly aware of my stomach.	1	2	3	4	5	6	7

Appendix E: Psychometric properties of measures

CFS/ME symptomology

Fatigue was assessed using the 11-item *Chalder Fatigue Scale* (CF-Scale; Chalder et al., 1993; Cella & Chalder, 2010), which is well validated again the Oxford (Sharpe et al., 1991) and Fukuda et al. (1994) criteria of CFS. For each item participants were asked to rate the frequency of symptoms: "less than usual", "no more than usual", "more than usual" and "much more than usual". Caseness was determined using the bi-modal scoring system, where the first two responses are scored “0” and the third and fourth responses are scored “1”. A score of 4 or more indicated caseness (Cella & Chalder 2010). Cella & Chalder (2010) found that the mean bimodal scores for CFS sufferers was 9.14 (SD = 2.73) and for community samples was 3.27 (SD = 3.21). The mean Likert score for CFS sufferers was 24.4 (SD = 5.8) and for community samples was 14.2 (SD = 4.6). Cella & Chalder (2010) found the CF-Scale can discriminate reliably between clinical and nonclinical conditions. In addition, it had good levels of internal consistency, with a Cronbach's alpha range between .88 and .9 (Chalder et al 1993).

IBS symptomology

The presence of IBS symptomology was screened using the 5-item *Irritable Bowel Syndrome Severity Scoring System* (IBS-SSS; Francis et al., 1997), which is validated against the Rome I criteria of IBS (Thompson et al., 1992). The original IBS-SSS used visual analogue scales to rate the severity of symptoms and their impact. A minor adaption was made, where the visual analogue were converted to Likert scales to ensure consistency across the questionnaires. The original scoring system was retained: each item generated a score between 0 and 100, leading to a total possible score of 500. A score of 75 or more indicates caseness. Mild, moderate and severe caseness are indicated by scores of 75 to 175, 175 to 300 and more than 300, respectively. Francis et al. (1997) found the IBS-SSS can discriminate reliably between clinical and nonclinical conditions, scores repeated within 24 hours were reproducible and sensitivity change pre/post treatment was good.

Psychological wellbeing

The *Patient Health Questionnaire* (PHQ-9) is a 9-item measure of depressive symptoms. The PHQ-9 used a Likert scoring of 0, 1, 2 and 3 to rate the frequency of depression symptoms, over the past two weeks, with a possible total score of 27. A score of 10 indicated clinical levels of depression. Scores of 5, 10, 15, and 20 represented mild, moderate, moderately severe and severe levels of depression, respectively (Kroenke et al., 2001). The PHQ-9 has been shown to have acceptable reliability and validity (Kroenke et al., 2001).

The *Generalised Anxiety Disorder* (GAD-7) is a 7-item measure of anxiety symptoms. The GAD-7 used a 4-point Likert scoring system to rate the frequency of anxiety symptoms, over the past two weeks, with a possible total score of 21. A score of 8 indicated clinical levels of anxiety. Scores of 5, 10, and 15 represented mild, moderate, moderately and severe levels of anxiety, respectively. The GAD-7 has been shown to have acceptable reliability and validity (Spitzer et al., 2006).

The level of functional impairment was assessed using the 5-item *Work and Social Adjustment Scale* (WSAS; Mundt et al., 2002). The measure was divided into work, home management, social leisure activities, private leisure activities, and family and relationships. Each component of the scale was assessed on a Likert scale ranging from 0 (not impacting at all) to 8 (impacting very severely). The total score ranged from 0 to 40. A score below 10 was associated with subclinical populations, a score between 10 and 20 indicated clinical functional impairment and a score above 20 signified moderate or severe impairment .(Mundt et al., 2002).

The 14-item *Short Health Anxiety Inventory* (SHAI; Salkovskis et al., 2002) was used to evaluate anxiety surrounding illness and somatic symptoms. For each item, participants were provided with four statements and were asked to identify the one that best described their feelings over the past six months. Responses were scored from 0 to 3. A total score of 42 could be obtained, and a score of 15 or more indicated clinical levels of health anxiety. The SHAI demonstrates good reliability, criterion validity and sensitivity to treatment (Salkovskis et al., 2002).

The 24-item Pain Self Perception Scale (PSPS; Tang et al., 2007) was used to measure mental defeat. For this study it was referred to as M*ental Defeat* (MD). The scale provided a number of statements and asked participants how strongly they agreed with each statement along a 5-point Likert scale (0 = “Not at all”, 1 = “Very little”, 2 = “Moderately”, 3 = “Stongly” and 4 = “Very strongly”), generating a total possible score of 96. The PSPS has been shown to have good internal consistency (α=0.98) and good test-retest reliability.

Cognitive factors associated with physical conditions

There was a previous measure that explored illness perceptions (Moss-Morris et al 2002) but no previously validated measured could be identified that evaluated cognitions specific to the CBT model of MUS. Therefore, a 22-item *Beliefs about Physical Symptoms* (Beliefs-P) scale was developed for the present study. Consistent with the CBT understanding of the maintenance of MUS, the items were derived from themes in the literature relating to potentially unhelpful beliefs about the consequences (social and functional) and management of MUS symptoms. In addition, relevant items were adapted from the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002). Item examples include *“It’s embarrassing when my symptoms flare up”* and *“I should be able to control my symptoms”*. For each item participants are asked to rate the degree to which they agreed or disagreed with a statement using 10–point Likert rating scale.

The brief 8-item Beliefs about Fatigue Symptoms (Beliefs-F) scale, developed by Wilson et al. (2015) was used to measure potentially unhelpful beliefs about the negative consequences of activity and fatigue, and somatic attributions for fatigue. For each item participants are asked to rate the degree to which they agree or disagree with a statement using a 10–point Likert rating scale, for example, *“my fatigue problems can be caused by over-activity”* and *“my fatigue problems can be caused by stress”*. Wilson et al. (2015) found the Belief-F had good internal consistency in their sample.

The *Beliefs about Gastrointestinal Symptoms* (Beliefs-G) scale was developed for this study. With the authors' permissions, items consistent with the CBT model were taken from the Cognitive Scale for Functional Bowel Disorders (CSFBD; Toner et al., 1998) and from CBT-relevant themes in the literature, regarding potentially unhelpful beliefs about the cause, and consequences (functional and social) and management of gastrointestinal symptoms. This resulted in 13 statements, for example, "I worry about losing control of my bowels in public" and "It's embarrassing when I keep going to the bathroom". The original scoring format of the CSFBD was retained; for each item participants were asked to rate the degree to which they agreed or disagreed with a statement using a 10–point Likert rating scale.

Behaviour factors associated with physical conditions

No previously validated measures could be identified that specifically evaluated CBT-related behaviours in MUS. Therefore, the 18-*item Physical Symptoms and Behaviour* (Behaviour-P) scale was developed for the present study. The items were derived from themes in the literature relating to potentially unhelpful avoidance, withdrawal and safety-seeking seeking. For example, *"I ask for reassurance about my symptoms"* and *"I avoid attending social activities because of my symptoms".* For each item participants were asked to rate the degree to which they agreed or disagreed with a statement using 10–point Likert rating scale.

No previously validated measures could be identified that specifically evaluated fatigue-related behaviours. Therefore, a 9-item brief *Fatigue Symptoms and Behaviour* (Behaviour-F) scale was compiled for the present study. Relevant items from the Behavioural Activation for Depression Scale (BADS; Kanter et al., 2006) were adapted and other items were derived from behavioural themes in the literature that were related to managing fatigue symptoms e.g. withdrawal, avoidance, reduced/increased activity. For example, *"There were certain things I needed to do that I didn't do"* and *"Most of what I did was to escape from or avoid something unpleasant"*. The measure retained the scoring format used in the BADS. For each item participants were asked to rate the degree to which they agreed or disagreed with a statement using 6–point Likert rating scale. Items 2, 3, 4, 5 and 9 were reversed.

The Irritable Bowel Syndrome Behavioural Responses Questionnaire (IBS-BR; Reme et al., 2010) was adapted for this study and referred to as the *Gastrointestinal Problems and Behaviours* (Behaviour-G) scale. Items from the IBS-BR that were consistent with the CBT model were retained (e.g. potentially unhelpful avoidance and withdrawal safety seeking behaviours to manage gastrointestinal symptoms). This resulted in 16 statements, for example, *"After opening my bowels I check my stool for abnormalities"* and *"I wear baggy clothing when my stomach feels bloated or distended".* For each item participants were asked to rate the degree to which they agreed or disagreed with a statement using a 7–point Likert rating scale.

Appendix F: Analyses of General Psychological Characteristics

The ME/CFS and IBS groups did not significantly differ from each on the GAD-7 ($p = .95$) or the SHAI-14 ($p = .92$) but the ME/CFS groups scored higher on the PHQ-9 ($p < .001$), the WASA ($p < .001$) and the MD ($p < .05$). Similarly, the co-morbid CFS/IBS group scored significantly higher than the IBS group on the PHQ-9 ($p < .05$), the WASA ($p > .05$) and the MD ($p < .05$). In contrast, the ME/CFS group did not significantly differ from the comorbid CFS/IBS group on any of the measures: PHQ-9 ($p > .05$), GAD-7($p > .05$), SHAI-14 ($p > .05$), WASA ($p > .05$) and the MD ($p > .05$). Lastly, the HC group scored significantly lower than the others group on all measures ($p > .05$; for each comparison).

Appendix G: Tertiary Analyses

In terms of beliefs analyses, a significant main effect was not found for the within subject factor (beliefs scales), $F_{(1.7, 192.07)} = 2.94$, $p = .64$, $\eta_p^2 = .03$. A significant main effect was found for group, $F_{(3, 113)} = 23.56$, $p < .001$, $\eta_p^2 = .39$. This was modified by a significant interaction, $F_{(5.1, 192.07)} = 11.32$, $p < .001$, $\eta_p^2 = .23$. To understand the nature of the interaction simple main effects were completed. A significant group effect was found for Belief-P ($F_{(3, 132)} = 30.07$, $p < .001$, $\eta_p^2 = .41$), Belief-F ($F_{(3, 134)} = 18.27$, $p < .001$, $\eta_p^2 = .3$) and Belief-G ($F_{(3, 129)} = 13.3$, $p < .001$, $\eta_p^2 = .24$).

Regarding behaviours scales, a significant within subject main effect was found for behaviour scales, $F_{(2,236)} = 151.42$, $p < .001$, $\eta_p^2 = .56$. A significant main effect was found for group, $F_{(1,118)} = 19.66$, $p < .001$, $\eta_p^2 = .33$. This was modified by a significant interaction, $F_{(6, 236)} = 12.6$, $p < .001$, $\eta_p^2 = .24$. Simple main effects were completed in order to understand the nature of the interaction. A significant group effect was found for Behaviour-P ($F_{(3, 133)}=21.99$, $p < .001$, $\eta_p^2 = .34$), Behaviour-F ($F_{(3, 135)} = 7.53$, $p <.001$, $\eta_p^2 = .15$) and Behaviour-G ($F_{(3,132)} = 24.35$, $p < .001$, $\eta_p^2 = .36$).

The multiple comparisons indicate that on disorder-specific measures the co-morbid group showed characteristics of both CFS/ME and IBS. In relation to transdiagnostic measures the co-morbid group's scores were most similar to the CFS/ME group (see Table 7).

Appendix H - Author instructions for the Journal Cognitive and Behavioral Practice

GUIDE FOR AUTHORS

Introduction

Cognitive and Behavioral Practice is a quarterly international journal with the primary mission of clinical dissemination: to bridge the gap between published clinical research and the actual clinical practice of cognitive and behavioral therapies. *Cognitive and Behavioral Practice* publishes clinically rich accounts of innovative assessment and therapeutic procedures that are clearly grounded in evidence-based practice. The primary focus is on application and implementation of procedures. Accordingly, topics are selected to address current challenges facing practitioners, both in terms of technique, process, and the content of treatment. To meet this goal, articles may include rich descriptions of clinical interventions, examples of client-therapist dialog, embedded video clips readers can view on line, and/or significant case descriptions. This journal is for the practicing mental health clinician, instructors, and researchers with an interest in the clinical dissemination of their findings. Continuing education examinations are included in each issue.

Types of contributions

Teaching Clinical Strategies: These papers focus on educating the readership about how to conduct assessments and/or treatments with particular populations within an empirically supported framework. They must include case illustrations and preferably will include transcript material or video demonstrations. Teaching about other aspects of Clinical Practice: These papers might deal with supervision, legal and ethical issues, managed care issues, or giving legal testimony, for instance. There is no limit on the topics as long as they are relevant to clinical practice. Research Reports: These are papers that present clinically relevant research results. They may present new data on assessment, treatment or psychopathology. If they are short articles, the authors need only to point out briefly the clinical utility of the findings. Longer papers must include detailed case illustrations and, hopefully, transcript material to make the research findings clinically realistic and immediate. Treatment Development Reports: These papers might describe the theoretical foundation and iterative process used to develop a novel intervention or describe how an established treatment is adapted to a novel population or clinical setting. These papers might highlight issues of acceptability, feasibility, and initial outcomes, but competitive papers will highlight detailed description of the structure, strategies, and techniques the treatment employs. Case examples and/or video clips of interventions are encouraged that highlight how the treatment is implemented and how barriers/challenges are addressed. Special Series: These are collections of papers focusing on a special clinical topic. There is a Series Editor who develops the theme and then invites other clinicians and scientists to write topical papers that fit into the theme. Case Conferences: Like special series, case conferences are a collection of papers that focus upon a theme; in this instance, it is how to assess and treat a particular patient. The Case Conference Organizer writes up a detailed description of a case and selects four to eight Case Conference Respondents. The Case Conference Respondents write 6- to 20-page papers describing how they would assess and treat the patient. Also, the Respondents attend to special issues involved with treatment. Typically, the Organizer writes up a summary of the similarities and differences among the approaches taken by the Respondents. Expert Clinical Commentaries: These are brief articles (solicited and unsolicited) in which experts in the field comment on the most up-to-date clinical topics, controversies, or discoveries within their expertise, and/or comment on an agenda for clinical research. These are roughly 3,000 words in length and are structured as a launching point for clinical practice and/or future clinical research. Clinical Reviews. These are regular length review articles that focus specifically on clinical strategy and existing evidence base for that strategy.

Contact details

Questions about the appropriateness of a manuscript for Cognitive and Behavioral Practice should be directed (prior to submission) to the Editorial Office, at bonnieb@bu.edu (Bonnie Brown, Editorial Assistant, Cognitive and Behavioral Practice, Center for Anxiety, Boston University, 648 Beacon Street, 6th Floor, Boston, MA 02215).

BEFORE YOU BEGIN

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State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

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Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Results
Results should be clear and concise.

Discussion
This should explore the significance of the results of the work, not repeat them. Avoid extensive citations and discussion of published literature.

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Glossary
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Only original papers will be considered. Manuscripts are accepted for review with the understanding that the same work has not been and will not be published - nor is presently submitted - elsewhere, and that all persons listed as authors have given their approval for the submission of the paper; further, that any person cited as a source of personal communications has approved such citation. Written authorization may be required, at the Editors' discretion. Articles and any other material published in Cognitive and Behavioral Practice represent the opinions of the author(s) and should be construed as reflecting the opinions of the Editors, the Association, or the Publisher.

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A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

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Acknowledgements

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Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.
Reference to a website:
Cancer Research UK. Cancer statistics reports for the UK. (2003). http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/ Accessed 13.03.03.

Appendix I: Ethical approval

FW: Ethics 14-164

psychology-ethics

Mon 21/03/2016 15:15

To:Hazel Carrick <H.Carrick@ bath.ac.uk>;

Dr Michael J Proulx
Chair, Psychology Research Ethics Committee

-----Original Message-----
From: Psychology Ethics Committee [mailto:psychology-ethics@ bath.ac.uk]
Sent: 02 July 2014 13:46
To: Hazel Carrick <H.Carrick@ bath.ac.uk>
Subject: Ethics 14-164

Dear Hazel Carrick

Reference Number 14-164

The ethics committee have considered your ethics proposal for the study entitled 'The new OCD-UK Annual Conference: Building understanding of OCD and its treatment' and have given it full ethical approval.

Best wishes with your research.

Yours sincerely

--
Dr Helen Lucey
Chair Psychology Ethics Committee
University of Bath

Information about making an ethics application can be found at
http://moodle.bath.ac.uk/course/view.php?id=52192

Appendix J: Pre- and post-questionnaires

Pre Questionnaire - Experience & Expectations of the Day

Your Connection to OCD Please tick as appropriate	
Sufferer	
Parent with child under 18	
Parent with child over 18	
Spouse/partner	
Other family member	
Friend	
Health Professional	
Other (please state) _____	

For OCD sufferers only	
Have you received treatment for OCD? Please tick as appropriate	**Yes** **No**
Medication	
Cognitive Behavioural Therapy (CBT)	
Exposure Response Prevention (ERP)	
Systemic or Family Therapy	
Psychodynamic Therapy	
Counselling	
Other (please state) _____	

Please rate how *confident* you currently feel about:				
	Very confident	**Quite confident**	**Not very confident**	**Not at all confident**
Your understanding of OCD?				
Your knowledge of the treatment options available for OCD?				
Your knowledge of the evidence base for those treatment options?				
Your ability to discuss treatment options with professionals?				
Your ability to discuss treatment concerns with professionals?				

What are your expectations and hopes for attending this conference?

Please give details:

Please turn over

Pre Questionnaire - Your Understanding of OCD and its Treatment

People develop beliefs about a condition from past experience, the media, and other influences. Please complete the following anonymous questionnaire about you beliefs about OCD.

Please rate each item on a scale from 0 to 100, where **0 indicates "Do not agree at all" and 100 indicates "Completely agree".**

Question	**Rating from 0 to 100: (0 "Do not agree at all" - 100 "Completely agree").**
1. OCD is caused by a chemical imbalance in the brain.	
2. OCD is a psychological problem	
3. I believe that obsessional problems can be overcome.	
4. I am certain that only psychological therapy can help me (my relative/partner/friend) to beat OCD.	
5. I am certain that only medication therapy can help me (my relative/partner/friend) to beat OCD.	
6. There's something wrong with me (my relative/partner/friend) as a person which means that I'm (he/she is) unlikely to overcome the obsessional problem.	
7. The fact that I have (my relative/partner/friend has) OCD means there is something physically wrong with me (him/her).	
8. I (my relative/partner/friend) have received good therapy for the OCD in the past.	
9. I (my relative/partner/friend) have received the wrong therapy for the OCD in the past.	
10. I (my relative/partner/friend) have not had enough therapy.	
11. OCD is a chronic condition which can be managed but not cured.	
12. I am optimistic that I (my relative/partner/friend) will be able to overcome the OCD.	
13. In my experience, most therapists don't understand OCD.	
14. I have (my relative/partner/friend has) not made as much progress in beating OCD as I (he/she) would have liked to, because of faults of my (his/her) own.	
15. I have (my relative/partner/friend has) not made as much progress in beating OCD as I (he/she) would have liked to, because of not having received good enough therapy.	
16. I have (my relative/partner/friend has) not made as much progress in beating OCD as I (he/she) would have liked to, because OCD is a difficult problem to beat.	
17. I (my relative/partner/friend) have not made as much progress in beating OCD as I (he/she) would have liked to, because of other life difficulties.	

18. I have (my relative/partner/friend has) not made as much progress in beating OCD as I would have liked, due to bad things that have happened to me (him/her) when I (he/she) was younger.	
19. The therapy I have (my relative/partner/friend has) had on the past has not focussed sufficiently on the obsessional problem.	
20. Over time I have become more and more pessimistic about the chances of beating OCD.	
21. Over time my understanding of how OCD works has increased.	

Post Questionnaire - Feedback

Please rate the overall *content* of the day on the following:				
	Very good	**Quite good**	**Not very good**	**Not at all good**
Interest of topics				
Quality of presentations				
Relevance to you				
Helpful for developing confidence to work with professionals				
Positive impact on your feelings about OCD treatment				

Please rate how *confident* you currently feel about:				
	Very confident	**Quite confident**	**Not very confident**	**Not at all confident**
Your understanding of OCD?				
Your knowledge of the treatment options available for OCD?				
Your knowledge of the evidence base for those treatment options?				
Your ability to discuss treatment options with professionals?				
Your ability to discuss treatment concerns with professionals?				

How well did the day meet your expectations?

Very Well ☐ **Quite Well** ☐ **Not Very Well** ☐ **Not at all Well** ☐

Please give details:

What changes, if any, would you like to see in future Conferences?

Please give details:

Please turn over

Post Questionnaire - Your Understanding of OCD and its Treatment

People develop beliefs about a condition from past experience, the media, and other influences. Please complete the following anonymous questionnaire about you beliefs about OCD.

Please rate each item on a scale from 0 to 100, where **0 indicates "Do not agree at all" and 100 indicates "Completely agree".**

Question	**Rating from 0 to 100: (0 "Do not agree at all" - 100 "Completely agree").**
1. OCD is caused by a chemical imbalance in the brain.	
2. OCD is a psychological problem	
3. I believe that obsessional problems can be overcome.	
4. I am certain that only psychological therapy can help me (my relative/partner/friend) to beat OCD.	
5. I am certain that only medication therapy can help me (my relative/partner/friend) to beat OCD.	
6. There's something wrong with me (my relative/partner/friend) as a person which means that I'm (he/she is) unlikely to overcome the obsessional problem.	
7. The fact that I have (my relative/partner/friend has) OCD means there is something physically wrong with me (him/her).	
8. I (my relative/partner/friend) have received good therapy for the OCD in the past.	
9. I (my relative/partner/friend) have received the wrong therapy for the OCD in the past.	
10. I (my relative/partner/friend) have not had enough therapy.	
11. OCD is a chronic condition which can be managed but not cured.	
12. I am optimistic that I (my relative/partner/friend) will be able to overcome the OCD.	
13. In my experience, most therapists don't understand OCD.	
14. I have (my relative/partner/friend has) not made as much progress in beating OCD as I (he/she) would have liked to, because of faults of my (his/her) own.	
15. I have (my relative/partner/friend has) not made as much progress in beating OCD as I (he/she) would have liked to, because of not having received good enough therapy.	
16. I have (my relative/partner/friend has) not made as much progress in beating OCD as I (he/she) would have liked to, because OCD is a difficult problem to beat.	
17. I (my relative/partner/friend) have not made as much progress in beating OCD as I (he/she) would have liked to, because of other life difficulties.	

18. I have (my relative/partner/friend has) not made as much progress in beating OCD as I would have liked, due to bad things that have happened to me (him/her) when I (he/she) was younger.	
19. The therapy I have (my relative/partner/friend has) had on the past has not focussed sufficiently on the obsessional problem.	
20. Over time I have become more and more pessimistic about the chances of beating OCD.	
21. Over time my understanding of how OCD works has increased.	

Appendix K: Instructions to Authors for Journal of Applied Research in Intellectual Disabilities

Journal of Applied Research in Intellectual Disabilities - Author Guidelines

Crosscheck

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read

that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and Letters to the Editor are accepted. Theoretical Papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the Journal of Applied Research in Intellectual Disabilities should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
Running Title: A short title of not more than fifty characters, including spaces, should be provided.
Keywords: Up to six key words to aid indexing should also be provided.
Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.
Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.
-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:

-Emerson E. (1995) Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. Mental Handicap Research 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:

http://www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here:

http://www.refman.com/support/rmstyles.asp

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Appendix L: Data abstraction form

Reference:	
1st review date:	
1st check by:	
2nd review date:	
2nd check by:	
Title:	
Authors:	
Year:	
Type of publication:	
Publication source:	
Country completed:	
Funding source:	
Ethical issues:	
Conflict of interest/perspective:	
Focused aims or research questions:	
Key words:	
Design type:	
Setting:	
Sample size:	
Inclusion/exclusion criteria:	
Assessment/screening:	
Source of recruitment:	
Date of recruitment:	
Reliability & credibility of measurements:	
Methodology:	
Analysis:	
Reliability & credibility of analyses:	
Effect size (if relevant):	
Findings:	
Justifiable conclusions:	
Research implications	
Clinical implications	

CRL Appendix M: Critical Appraisal of a Case Study (Centre for Evidence-Based Medicine).

Appraisal questions	Addressed		
	Yes	Can't tell	No
1. Did the study address a clearly focused question / issue?			
2. Is the research method (study design) appropriate for answering the research question?			
3. Are both the setting and the subjects representative with regard to the population to which the findings will be referred?			
4. Is the researcher's perspective clearly described and taken into account?			
5. Are the methods for collecting data clearly described?			
6. Are the methods for analyzing the data likely to be valid and reliable? Are quality control measures used?			
7. Was the analysis repeated by more than one researcher to ensure reliability?			
8. Are the results credible, and if so, are they relevant for practice?			
9. Are the conclusions drawn justified by the results?			
10. Are the findings of the study transferable to other settings?			

The descriptive quality and transferability of the study (i.e. focus or research question, situation of the setting and sample, perspective of author) was determined using the following questions: 1, 3, 4 and 10. The robustness of the case study methodology (i.e. the design, methodology and analysis used) was evaluated using the following questions: 2, 5, 6, 7, 8 and 9. For the purposes of this review, study quality was categorised as poor, acceptable, good and very good. Please find a description for each category below.

Study quality category	Description
Poor	Failed to adequately address a minimum of five of the descriptive or methodological appraisal questions.
Acceptable	Adequately addressed at least three of the descriptive appraisal questions but did not sufficiently address the methodological appraisal questions (less than two).
Good	Adequately addressed the descriptive appraisal questions (at least three) and some of the methodological appraisal questions (at least four).
Very good	Adequately addressed most the descriptive (three or more) and methodological (five or more) appraisal questions.